The Survival Guide

Living with Acquired Brain Injury in the Community

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For ease of reading we have used the pronoun he throughout the book. This was done for simplicity only and is not meant to imply any gender bias.

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Introduction

This guide has been written to provide information and support to families of persons who have had a moderate to severe brain injury. Since each brain injury is different, not all information will apply to every family. It is the hope of ABI Outreach Teams that the guide will assist families in the journey toward a new "normal" in the first year or two following the brain injury.

This book offers general information on issues you may encounter during the establishment of a new life following brain injury. It is not designed to replace any information provided by the health professionals working with you and your family member.

Recovery from brain injury is a long process. Great improvements are seen in the first year, but progress may continue for many years. Your family's adjustment is also a long process. In this book, we hope you will find some expression of your own experience - that you will realize you are not alone and your responses to this sudden and major change in life are normal. As Jean Church has said,

"You can come out of the furnace of trouble two ways: if you let it consume you, you come out a cinder; but there is a kind of metal which refuses to be consumed and comes out a star."

We hope this book provides you with support to help you come out a star.

★ ★ ★

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Background On Brain Injury

Background on Brain Injury

Acquired Brain Injury

Many things can damage the brain. This book is for families of survivors of an "acquired brain injury." Not all brain injuries are acquired brain injuries. To be an acquired injury the survivor must have hurt his brain during his lifetime. He can't be injured at birth. Also, the damage must be the result of an injury or an illness, but not an illness that gets worse with time, like Alzheimer's disease or multiple sclerosis.

Examples of acquired brain injury include:

- ★ Traumatic brain injury, like a blow to the head or hitting one's head,
- ★ Brain tumours,
- ★ Brain infections, like meningitis and encephalitis,
- ★ Lack of oxygen, like what happens when someone almost drowns,
- ★ Strokes,
- ★ Violent shaking, as in Shaken Baby Syndrome or some whiplash injuries.

How Brain Damage Happens

Brain damage results from changes to the brain caused by the injury or illness. Each injury or illness acts in different ways. Some common ways in which the brain is damaged include:

- ★ Bruising,
- ★ Bleeding (also called a hematoma,)
- ★ Brain swelling,
- ★ Fever,
- ★ Lack of blood or oxygen to the brain (also called hypoxia and anoxia,)
- ★ Shearing or tearing of brain cells when the brain is rapidly moved back and forth or twisted around (also called Diffuse Axonal Injury,)
- ★ Pressure inside the skull (called increased intracranial pressure,)
- ★ Objects taking up space in the brain (like tumours.)

An acquired brain injury can lead to either local or diffuse damage. Local damage is said to happen when only one or a few parts of

The brain can be damaged by bruising, bleeding, swelling, fever, lack of oxygen and strong rapid forces.

the brain are hurt. The survivor injured in this way usually notices only a few changes. He might have trouble talking or drawing a picture. Diffuse damage happens when many parts of the brain are injured. Survivors of this type of damage usually find many changes. Below are examples of local and diffuse damage.

- ★ In a car crash a person's head can hit the dash board. If this happens, the front of the brain will hit the front of the skull. Where the brain hits the skull, it can be bruised or scraped. This damage is local because it happens only to the front of the brain.
- ★ A person can also have diffuse damage in a car crash. The brain is made up of millions of tiny cells. These cells connect the different parts of the brain to each other, but they are not very strong. In a crash where the brain moves rapidly back and forth, these brain cells are stretched and torn. This leads to tiny points of damage throughout the brain. This is an example of Diffuse Axonal Injury.

Parts of the Brain and How Injury Affects Them

Different parts of the brain help you do different things. Below are descriptions of parts of the brain that are often talked about. The descriptions include where the part is, what it usually does and what behaviors a person might see after it is damaged.

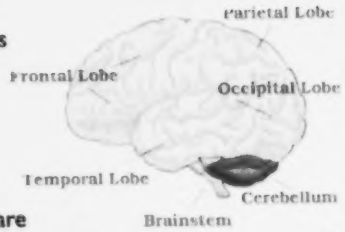
Frontal Lobe

The part of the brain just behind your forehead is called the frontal lobe. It is further divided into front and back areas. The front is called the prefrontal area. This part of the brain helps a person do the following:

- ★ Plan and organize,
- ★ Solve problems,
- ★ Pay attention or shift attention,
- ★ Control impulses,
- ★ Get started on something,
- ★ Be aware of one's strengths and weaknesses,
- ★ Be aware of what others are thinking and feeling.

A survivor with an injury to this part of his brain sometimes seems like a different person. He might appear more forward or rude than before. His activity level might drop. He may even sit back and do nothing, unless told to. Many survivors are more distractible than before the injury or illness. Others complain of not being able to get organized. Tasks like planning parties and even deciding what to wear can become a chore for these people. In many cases these problems are made worse because the

survivor may either not be aware of these changes or does not realize how others are affected by them.



The back area of the frontal lobe includes the precentral and the premotor areas. They are involved with planning the movements of the body. Damage to this part of the brain leads to problems starting and coordinating movements of arms, legs and other body parts. Things like opening or closing one's hands can take much thought and effort after this kind of damage.

Temporal Lobes

Your temporal lobes are located along the sides of your head above your ears. This part of the brain helps a person to:

★ Understand things that you hear,
★ Remember things you see and hear,
★ Feel emotion.

Your right temporal lobe helps you understand and remember things like pictures, faces and sounds you can't put a name to, like a piece of music. Your left temporal lobe does things like understanding and remembering words, talking and doing math. Both lobes help you to feel emotion. A person with damage to this part of the brain may be unable to speak, to understand others, to read, to recognize faces or to do math. He may have memory problems. The survivor might also have trouble controlling his emotions, especially anger.

Parietal Lobe

Behind your frontal lobe and between your temporal lobes is the parietal lobe. It is at the top of your head. This lobe is where information from sight, hearing and touch are brought together. This area helps a person do the following:

★ Feel the touch of something (hard or soft, rough or smooth,)
★ Know where one's body parts are (my hand is on my lap,)
★ Know where you are,
★ Coordinate seeing and moving (for example, hand-eye coordination,)
★ Draw,
★ Read, write and do math problems.

The survivor with damage to this lobe might get lost easily. He might have strange sensations or have trouble reaching for things around him. The survivor might not recognize his spouse's face, be unable to read a map or be unable to draw a simple shape. He may also have problems with speaking, writing, reading and arithmetic.

Occipital Lobe
Behind the parietal lobes, at the back of your brain, is the occipital lobe. This part of your brain helps you to understand things that your eyes see. Problems with blindness and recognizing everyday things, like a toaster or a lamp, result from damage to this lobe. Survivors with damage to this lobe have trouble naming colors, shapes and other things they see. The survivor may also have blind spots. All of these problems, however, are rare.

Cerebellum
Your cerebellum is at the very back and bottom of your brain. This part of your brain helps to make the movements of your body smooth and coordinated. Damage here can lead to poor balance, jerky movements and shrinking of muscles. This can lead to problems with many everyday activities like walking, talking, and eating.

Brain Stem
Where the brain connects to the spinal cord is your brain stem. This part of your brain controls "involuntary functions" of your body, like your breathing and heart rate. It also controls how awake or sleepy you are. All of the nerve fibres that connect the different parts of your body to your brain travel through your brain stem. After a brain stem injury, the survivor usually has trouble moving some part of his body. He may have an unusual walk or may have to use a wheelchair. His speech may be a little slurred or he may not be able to talk at all.

Severity of Brain Injury

When someone in your family is injured, everyone wants to know, "how bad is it?" and, "will he be normal again?" It is difficult to answer these questions. This is because there is no way to perfectly predict how much a person will recover. Health professionals sometimes use the severity of the injury as an indicator of "prognosis." Prognosis is a medical term meaning how well a person will do in the long run. With traumatic brain injuries the terms "mild," "moderate" and "severe" are used to judge prognosis.

For traumatic brain injuries the judgment of severity is based on the survivor's ability to respond to others or remember. Ability to respond is measured using the Glasgow Coma Scale (GCS). Scores on the GCS range from 3 to 15. The score is based on the survivor's ability to talk, to do what he is told, and to make eye contact. A GCS score of 8 or less is a severe injury. Survivors who score this low are said to be in coma.
A score of 9 to 12 is a moderate injury.
A score of 13 or higher is a mild injury.

Severity of injury is a good predictor of recovery. How the survivor is doing now is a better measure of how the survivor will do in the future.

Another measure of severity is the survivor's ability to learn new information. After an injury people often cannot remember what has just happened. They don't know that they are in hospital or what day it is. This inability to remember is called post-traumatic amnesia or, for short, PTA. PTA of greater than 24 hours is a sign of a severe injury. The injury is called moderate if the PTA lasts between 1 and 24 hours. A mild injury is diagnosed if the PTA is less than 1 hour.

Severity of injury is a good predictor of recovery. The usual rule of thumb is the more severe the injury the less likely the survivor will return to normal. After a mild injury 90 percent of individuals will be back to normal in a couple of days. Most survivors of a severe injury will never regain all of their lost skills. Only a small portion of them will return to work or successfully complete school.

Mild brain injury

This book is directed at families of persons with moderate to severe brain injury. This description of mild injury is included for completeness.

Persons with mild brain injury usually are not admitted to hospital. Most frequently, the injury results from a blow to the head caused by a fall or sudden violent motion, such as a car crash. The survivor may have one or more of the following symptoms:

- ★ Brief loss of consciousness,
- ★ Loss of memory from immediately before or after the injury,
- ★ Dizziness or clouded thinking at the time of the injury.

Medical tests often do not show any damage to the brain. Symptoms of a mild brain injury are often temporary, disappearing gradually over a period of a couple of days to three months. Recovery is considered complete if symptoms do not interfere with daily functioning.

Persons with mild brain injury have fewer and less severe symptoms for a shorter period of time than persons with more severe injuries. The most common symptoms include:

- ★ Headaches,
- ★ Dizziness,
- ★ Tiredness,

★ Trouble paying attention,
★ Memory problems,
★ Poorer problem solving skills,
★ Irritability,
★ Minor language problems,
★ Personality changes and bursts of emotion.

It is important that someone who thinks that he has had a mild brain injury see a health professional who is experienced in treating brain injury. Health care professionals without this experience may brush the injury off because it is mild. A knowing professional can give information and encouragement to help the survivor as he recovers.

Moderate brain injury

Moderate injuries lead to a number of problems. Some of them are seldom seen in mild injuries. They include:

★ Physical problems (poor balance, problems with vision, headache, fatigue, physical disabilities, such as problems walking, sitting, etc.,)
★ Problems in everyday living (poor memory and attention, difficulties planning and setting goals, slowed thinking, problems understanding others or speaking clearly,)
★ Problems with emotional control (problems controlling one's temper, shifting emotions, lack of emotion, increased anxiety,)
★ Problems with motivation and self-control (poor hygiene, low sexual drive, lack of initiation, impulse buying, aggression, saying inappropriate things,)
★ Social problems (difficulty making or keeping friends, poor judgment in groups, standing too close to others, saying the wrong thing, not picking up cues that people are tired, angry or bored.)

Changes after a moderate injury are more likely to interfere with life than those after a mild injury. A minority of moderate injury survivors will not successfully return to home, work or school and may require ongoing support.

Recovery from a moderate injury may take months. Some changes will be permanent.

Severe brain injury

Types of changes after a severe injury are the same as those listed for moderate injuries. The difference is that the survivor with a severe injury will have more symptoms with greater problems that last longer. Physical disabilities and difficulties taking care of oneself are common in this group. A number require the use of an aid, like a wheelchair or a speech synthesizer. Some will never live on

their own, but require others to take care of them. Cognitive changes are also more common and more severe in this group. Examples of changes to thinking ability used in the previous section on parts of the brain are most likely to be from a survivor of a severe injury. Finally, the likelihood that a person will return successfully to school, to work and to caring for their home is lowest in this group. Some research says that only 30 to 40 percent of these survivors will go back to something like their old life style.

Limits of Measures of Severity

Knowing that an injury is mild, moderate or severe tells us how bad things may be. But it is not a perfect measure. Each injury is different and each survivor is affected differently. There are stories of people so severely injured that they were near death but who recovered and went on to university. There are also stories of people with much less severe injuries whose lives have fallen apart. Measures of severity are, at best, a guide. It is how the survivor is doing now and the gains that he has made that tell us best where he is going.

Notes

After The Hospital

After The Hospital

This chapter provides information on two topics that survivors and their families have consistently identified as very important, both inside and outside of hospital.

- ★ Reasons for discharge and/or decrease in medical or therapy services.
- ★ Resources that survivors and their families can access to find information on brain injury.

Discharge and Reduced Therapy

Questions about Discharge

When discharge approached, you may have wondered why the survivor had to leave the hospital. This is a common concern and reflects people's fears about having to take care of the survivor. These fears are often greatest when the injury has been severe, causing marked changes in the survivor's ability to think, get around, take care of himself, and manage his feelings and behaviours. In these situations, the move out of hospital is yet another major life change. If you are like others, you may have questioned discharge because the survivor still had needs and you felt the move out of hospital or into rehab was too quick.

The simple answer is that the survivor gained what he could from his hospital or rehab stay, and needed to move on to make further gains - gains that could not otherwise be achieved. Research has shown that an earlier move to a rehabilitation ward improves recovery for many.

Discharge from hospital usually happens once the survivor is medically stable; discharge from a rehabilitation ward, when their treatment goals have been achieved.

Not every survivor of a brain injury goes to a rehabilitation ward, and some who do are discharged before meeting treatment goals. The survivor may not need the regular, daily treatment provided in a rehab ward, or they may not be ready for the intense level of treatment offered in rehab. Those who are not ready may be sent to a long-term care

Going home is a chance for independence that is hard to achieve in hospital

centre or back home. To you and the survivor, this may feel like "being put on the shelf." Remember, some individuals experience a slower recovery, but do improve to the point where they are ready for more intense treatment. It may take months or even years. When ready, however, the survivor can return to the rehabilitation unit.

The return home has benefits over staying in hospital. You may spot strengths and weaknesses at home, school or work that would not be seen there. Once identified, these can be brought to the attention of health professionals. Finally, going home is a chance for independance that is hard to achieve in hospital.

Dealing with Discharge

You and the survivor can make the stress of discharge a little easier by taking the following basic steps.

★ First, get organized. If you have not already done so, start a binder or folder containing reports, handouts, notes from meetings, lists of names and phone numbers. Include anything that forms a record of the survivor's care and could be used to help him, you or other family members to better understand the injury and its consequences.

★ Second, when a problem arises, get in touch with someone who has provided care in the past. It is often not until the survivor returns home or resumes school or work that problems are seen. When activities are first attempted, unexpected problems may arise. This is the time to contact professionals to assist in meeting the new challenges.

Questions about Therapy

You may also feel the survivor's therapy is being limited. This concern usually arises when outpatient or community therapy, often provided by an occupational therapist, physiotherapist, social worker, speech-language pathologist or recreation therapist, is reduced.

Again, it is a matter of determining what will provide the greatest benefit to the survivor. Many therapists believe that life is the best therapy. Healthy people, for example, need to take care of themselves, engage in regular exercise, and find thought-provoking stimulation. Instead of visiting a therapist, the experience of living motivates them; that is, life provides exercise, stimulation, and train-

ing. Life can provide similar benefits for the survivor. Even where the survivor may always need someone to assist him in living, that person need not be a therapist. A family member, friend, home health aide, or community worker could assist him.

Independence is another reason to move on. Therapists believe that limiting the length of therapy can help the survivor maintain his independence. If the survivor is relying on a therapist to keep fit and active, he is not being given the chance to take care of himself. Feeling responsible for one's own life can be a powerful feeling. Individuals who have been given greater control over dressing themselves, feeding themselves and doing everyday chores have shown amazing improvements in mood, conduct, and feelings of self-worth. Some have even shown they are capable of doing much more for themselves.

The Impact of Limited Resources

The final part of the explanation for discharge and/or reduced therapy is that there is only so much service available; there are only so many beds and so many people to provide services. In rural or northern Saskatchewan, limits on available service may be the factor in deciding to discharge and/or reduce therapy.

★ In cases of discharge or reduced therapy due to limited resources, your only recourse is advocacy. Go to your health board, band, or political representative and apply pressure to get better services.

Finding Information on Brain Injury

Another frequent concern for family members is finding enough information on brain injury. This is not to say that nurses, doctors, social workers and therapy staff have not done enough teaching. In fact, they have likely been providing you with information - sometimes more, sometimes less - since the injury.

This information may include diagnosis (the name given to the survivor's type of brain injury); prognosis (how the survivor is likely to do after they leave hospital); continuing therapy in the home; keeping safe and well; dealing with future difficulties; and making arrangements for services in the community. For several reasons, you may still want to know more.

★ There always seems to be more to learn. As you and the survivor face new challenges, the need for additional information may grow.

★ Information provided in meetings with hospital staff or community workers may not "sink in", meaning you may have been too tired or emotional to fully understand or remember it, or the survivor may have memory or comprehension difficulties that prevent him from retaining it.

★ You may want the "big picture", meaning you want more in-depth information on brain injury, its usual course, common and not-so-common problems, changes you might expect in your family, how to return to school or work, how to work within the health care system or other organizations, and so on. This type of information is usually provided a little at a time, usually when there is a relevant problem or issue at hand.

★ Finally, there are times when the information you want just isn't made available. This usually occurs when the survivor's stay in hospital is short, due to a less severe injury and quicker physical recovery.

Finding More Information

The solution to feeling uninformed is to gather as much information as possible. There are books, manuals, pamphlets and videos your whole family can use. There are sources listed at the end of several chapters in this resource guide and in the Resources chapter.

★ For help in your search, contact the Saskatchewan Brain Injury Association (SBIA), Lloydminster and Area Brain Injury Society (LABIS), Acquired Brain Injury Outreach Teams, or Acquired Brain Injury Coordinators (if your health district has one). See the Resources chapter for contact numbers.

★ Search the Internet. The Resources chapter has several suggested sites to help you get started.

★ Talk to local community therapists, staff at the hospital where the survivor was treated, or volunteers or workers with health agencies and/or groups. See list of Agencies in Resources chapter.

★ Talk with survivors and families of survivors who have gone through similar experiences. You may find their stories helpful and inspiring.

In your discussions with others, do not be afraid to ask to have things repeated or explained more than once. Yes, the information may have been provided in hospital or by a community worker, and yes, it may have been repeated several times already - none of that matters. What matters is that you understand the information. Always feel free to have information repeated again.

Helping Rebuild Skills

Helping Rebuild Skills

Everyone needs a helping hand at one time or another. When it comes to dealing with a family member with a brain injury, however, the question of helping is not always clear-cut. How much help do you provide? How much help is the survivor willing to accept? Many factors may influence his willingness to accept help.

★ Prior to injury did he tend to be independent or dependent, trusting or cautious, easy-going or difficult?

★ Has his ability to think been affected? For example, does he have memory problems, has his thinking slowed down, does he show poor judgment?

★ After his stay in hospital, does the survivor expect others to cater to him? This can affect his willingness to do things for himself.

★ How does the survivor feel about the changes in his life? Is he angry or depressed? Does he understand the changes?

With so many influences, it is not surprising there are no simple answers to questions of how much help you should provide or offer the survivor. The fact is, there is no "right" answer. The amount of help you provide depends on the survivor and your circumstances.

The Science of Helping

While there are no right answers in deciding how much help to provide, there are useful guidelines. The first suggestion is to approach helping like a scientist. Scientists always test their ideas; you can do the same with helping.

★ An added benefit of acting like a scientist is that helper and survivor can distance themselves from their emotions. Putting things to the test can avoid pitting helper against survivor and lead to mutual co-operation.

Rules to Remember

When putting things to the test, remember the following three rules.

1. The test must be safe. A good rule of thumb is to start small. If the survivor wants to cook a full meal, start with a breakfast of toast and cereal, or a lunch of grilled cheese sandwiches and soup. The results will give you and the survivor immediate feedback on any problem

The amount of help you provide depends on the survivor and your circumstances.

areas. If the test is a success, try something a little more difficult. If not, set more achievable goals or keep practicing to improve skills.

2. Do not assist if you feel uncomfortable. If the survivor wants to do something you feel is too dangerous, simply say no. Saying no gives him two important pieces of information. First, it lets him know what makes you uncomfortable, which helps him understand what to expect of you and others. Second, it helps him make safer decisions. Like many of us, the survivor may sometimes push too far. Your refusal can lead to negotiation and a safer test. Remember, it is always okay to speak your feelings and misgivings.

3. Natural consequences can be the best teachers. As a helper, it is important for you to allow natural consequences to follow actions, whether rewards or punishments. If the survivor waters the flowers, he enjoys credit for the beautiful blooms. If he burns the toast, he eats it burnt or throws it out.

The important point is that you do not bring on the rewards or punishments. When you let natural consequences occur, the survivor is less likely to blame you when things don't work out. It can also lead to fewer disagreements and an increased sense of self-control for the survivor.

What The Survivor Needs to Rebuild Skills

Insight

Insight is a sense of one's own abilities. For example, knowing you can jump down three stairs, but not ten, is insight. The brain injury may affect the survivor's insight. Insight may be slightly less than it was, markedly less, or as is the case with a small number of survivors, virtually gone. This is called lack of insight.

Survivors who suffer from lack of insight often need help to see the consequences of their actions. Regular and ongoing results of tests done with a helper can provide this. For example, you could put up a chart in the kitchen and add check marks each time the survivor successfully makes toast. This

provides him with clear, objective feedback and can help make up for his own lack of insight.

Initiation

Initiation is also necessary for people to rebuild their skills. Initiation is the drive that pushes us to do the things we want to do or feel we should do. Some survivors of brain injury lose their drive. They are less interested in doing things for themselves than before their injury. This is called lack of initiation.

As a helper, you may often find yourself doing a lot more than you would like for the survivor. Or you may find the survivor does things around you, but not without you. Ask yourself, what needs to happen to get the survivor to do things for himself?

- ★ Find something that motivates the survivor. Does he need praise every time something is done? Can you offer rewards that are powerful enough to get him going?
- ★ Use reminders around the survivor, such as lists or signs that say what to do next, or verbal cues from helpers.

Motivation

Lack of initiation should not be confused with lack of motivation. People who lack motivation do not want to do what is asked of them. People who lack initiation want to, but cannot do it without encouragement.

Learned helplessness is one type of lack of motivation. It occurs when a person cannot or is not allowed to escape a situation that is hurtful or difficult. From this experience, they come to believe they have no control over their world and so lose motivation to help themselves. Some health workers believe learned helplessness can occur during the stay in hospital. Survivors who have learned helplessness may appear listless, depressed, and/or uninterested in things around them.

- ★ Encourage the survivor to do things. This will help him regain a sense of self-control, that is, the belief he can make a difference in his own life.

Conflicting Goals

The survivor has to want to rebuild his skills; this desire is not always present. You may want the survivor to do things to ease the burden of care, which can be very high, or health workers may recommend building certain skills. In both cases, the survivor may not want to do this. The result is that you become involved in a plan to build skills the survivor does not want.

Differences between you and the survivor may express themselves in two common

One way to reduce differences between you and the survivor is to involve him in planning the rebuilding of skills.

ways: passive resistance, when he agrees to work on a skill but does not practice it; and active resistance, when he argues or fights when you try to assist with the skill. Passive resistance is much more difficult to identify, but a key symptom is a feeling of dissatisfaction on the part of the helper. The reasons for your dissatisfaction will remain unclear until your differences are uncovered.

One way to reduce differences between you and the survivor is to involve him in planning the rebuilding of skills. Experience has taught health workers that a key to success is accepting goals for treatment from the survivor.

Accepting goals from the survivor may be even more important once he returns home, but it may take extra effort. He may be unable or unwilling to argue with health workers or caregivers. He may withhold his true feelings to keep the peace or because he does not want to offend. He may resist the whole process of planning to work on skills, because he wants to do it on his own or because he is upset by suggestions from others, such as how to behave appropriately.

- ★ In case of differences, review the situation. Having a third party may be useful in exploring the goals of the survivor and helper separately. The third party can then bring both together to develop a new plan for building skills.
- ★ Have everyone involved rate (on a scale of 1 to 10, for example) the importance and performance of, and satisfaction with the skills to be learned. This can serve to show more clearly differences between survivor and helper.

Another consideration is the needs of the family. Some of the survivor's goals must meet the needs of others, though the number of these goals should be small. These goals are more likely to meet resistance such as that described above.

How does your family want to continue providing support if the goals of the survivor differ from your own? This is usually more of an issue when caring for the survivor takes a lot of effort, and/or the survivor is resistant, lacking insight, or simply difficult.

- ★ When differences produce increased strain and dissatisfaction in your family,

consult a counselor, either as a couple or a family. Even if the survivor is unable to benefit from counseling, your family may. Counseling can help you explore your commitment to the survivor and concerns about providing care.

The discussion of the burden of care brings up an important issue. Should family members be the ones helping the survivor relearn skills? Supervision, especially after a severe brain injury, can be 24-hours a day. This can create relationships that lack the usual give-and-take, or where contrasting roles, such as lover and caretaker, form emotional conflicts within the helper. In most cases, family members are the only ones available to help relearn skills. If more community or financial resources are available, you may want to explore whether someone else can do this work. Someone from outside the family will not experience the same stress and strain, and may be able to provide the necessary direction and supervision without the emotional turmoil. Success at finding such a person, however, is usually limited, and the resource is often time-limited or places a heavy financial burden on the family.

Notes

The New Family

The New Family

Good or bad, life experiences change our families. Marriage, divorce, birth of a new child or death of a loved one are some that we know well. Each brings with it new responsibilities, new roles, new relationships and new feelings. The key to living with these changes is learning to adjust.

How well your family adjusts depends on the experience and your family. Adjustment is easier when the experience:

- ★ Is something that you want (like having a baby,)
- ★ Is short-lived (short-lived might mean weeks to months,)
- ★ Leads to few changes in the home.

Adjustment is easier when your family:

- ★ Likes challenges and looks for change,
- ★ Has a positive outlook (this may mean that they are denying some problems,)
- ★ Has family and friends who are willing to help,
- ★ Accepts help,
- ★ Has few other problems (like alcohol abuse.)

Living with a survivor of a moderate to severe brain injury is an experience that takes a lot of adjustment. This is not just something said to make you feel better. This statement is supported by research. For example, one study found that only autistic children are as challenging to parent as survivors of brain injury. Another study compared families after brain injury and spinal cord injury. It found that after six months the families with a spinal cord survivor had adjusted to the change. Families after brain injury were still struggling with the changes a year or more afterwards.

This is not to say that you and your family will have problems with adjustment. You may not. But if you do, you should know that it is quite normal. You should also know that there are things that you can do to help yourself. Often the first step is to try and understand the changes that have happened. Greater understanding usually leads to a sense of control. Feeling in control can reduce stress. Understanding can also help you to make better choices when managing the burden of caring for the survivor.

Living with a survivor of a moderate to severe brain injury is an experience that takes a lot of adjustment.

Changes in the Survivor

Changes to the family usually begin with the survivor. This is because it is what the survivor can and cannot do that decides what the family must do. Not all changes are alike, however. Some make a big difference to the family, while others don't. Below is a list of common changes. Those that families say are hard to adjust to are marked with a star. Go through the list below and check off the one's that apply to your survivor. This will help paint a picture of changes in him her since the injury or illness. (Changes marked with an asterisk are the most common.)

- ❑ Aggressive *
- ❑ Angry and critical *
- ❑ Attention problems
- ❑ Balance problems
- ❑ Double vision or wandering eye
- ❑ Easily distracted
- ❑ Emotional (anxious or depressed)
- ❑ Forgets appointments, etc.
- ❑ Headaches
- ❑ Immature
- ❑ Impulsive *
- ❑ Judgment is poor (bad decisions)*
- ❑ Lack of initiation (doesn't try things)
- ❑ Lacks insight (unaware of problems)*
- ❑ Lost easily
- ❑ Misunderstands what is said
- ❑ Moods are up and down
- ❑ Movements uncoordinated
- ❑ Poor problem-solving*
- ❑ Problems with reading or writing
- ❑ Says the wrong thing*
- ❑ Sensitive to noise *
- ❑ Sexual interest changed (more/less)
- ❑ Sleep problems
- ❑ Stands too close to others
- ❑ Swears/Verbally abusive*
- ❑ Talks too much
- ❑ Tires easily
- ❑ Trouble making decisions
- ❑ Worries too much

Increased Responsibilities

Now you have a picture of the changes to the survivor. The next step is to look at how these changes have increased family responsibilities. Family responsibilities are chores or duties that are done around the home that keep it working smoothly. How

much more you have to do can be a measure of how big the change has been in your home.

The next sections describe two different ways in which the survivor's changes may give you more to do. You can use the examples in these sections to help you think about how responsibilities have changed in your family. A helpful exercise might be to write a list of new responsibilities as you think of them.

Shifting Responsibility

Sometimes the survivor is not able to do things that he did before. The family's work increases because his responsibilities shift to you or other family members when this happens. Here are some examples of shifting responsibilities.

- ★ The survivor used to handle the money. Now he makes a lot of errors when doing the math. As a result, you are having to balance the cheque book.
- ★ The survivor used to help with meals. Now he forgets simple things like how much water to put in the rice. When he has problems like this he just doesn't cook. The result is you end up cooking all the time.
- ★ He used to watch the children when you went bowling. Now he's losing his temper with them all the time. You give up your bowling so that you can stay home and watch the children.
- ★ Your father used to take you to everything. Now he says embarrassing things and you find yourself going alone or asking your mother.

New Burdens

Some responsibilities may be totally new to your family. These are usually chores or duties the survivor did for himself before the injury or illness. Things that you might already have found yourself doing for the survivor include:

- ★ Taking care of him, such as getting him dressed, bathed or on the toilet,
- ★ Supervising the survivor,
- ★ Dealing with medical needs, such as giving medications or reminding about appointments,
- ★ Correcting the survivor or helping him to relearn skills,
- ★ Dealing with out of control emotions and behavior.

Changes in Roles

Changing responsibilities lead to changing roles. Roles are made up of

groups of chores that we do. For example, the role of housewife includes cooking, cleaning, watching the kids and so on. But there is more to a role. Being in a role means making decisions and taking authority. The housewife not only does the cooking, but decides what to cook and when. She also directs others to do things, like set the table.

Another way to understand the change in your family is to look at the shift in roles. Like responsibilities, the number of new roles can be a measure of how much more you are doing. As in the last section, you might try making a list of the new roles you and others have taken on.

We would also recommend that you look at how family members feel about taking on these new roles. For instance, roles bring work, but they also bring status. Status makes us feel better about ourselves. The family member who does more gets more credit. This can lead to feelings of being valued and important.

It is often the reverse for the survivor. He does less and is valued less. Survivors can react to this in a number of ways:

- ★ Grief as they realize they are not needed,
- ★ Anger at not being valued (especially where the survivor has poor insight,)
- ★ Apathy because of their inability to change things around them,
- ★ Relief because they can let go of responsibilities.

How the family feels about the survivor's loss of roles is also important. Many families feel guilty. This often happens when the survivor is unhappy with the changes. Other families struggle with the dilemma of how to include the survivor. If they make the decisions alone, they risk the survivor's anger. If they let him decide, they might not be able to live with the decision. Both options can lead to feelings of frustration, anger and resentment.

Finally, there is one change in role that spouses say is uniquely difficult; the shift from spouse to caregiver. A caregiver is a person that feeds, dresses and otherwise cares for another person. It is a common role for parents of young children. Being a caregiver for a spouse is unusual and can be very unrewarding. Spouses need give and take in

Shifting from spouse to caregiver is a role change that is unique and difficult.

their marriage. Many do not get that when they are a caregiver.

Changes in Relationships

Three things change relationships after brain injury:

★ Shifting roles,
★ Changes in the survivor's personality,
★ Less time for family members.

Shifting roles change relationships between the survivor and family members. A child who watches over his father does not give him the same respect. A wife who cannot banter with her husband and turn to him for advice does not feel she has a partner. A parent of an adult survivor does not expect the same independence.

Personality changes often alter how much you like the survivor. Likable changes can strengthen the relationship, like when a gruff father becomes warmer and kinder. Many times the changes lead to a less likeable person. At its worst the survivor changes so much that he seems like another person.

★ A wife described her experience as being widowed and married at the same time… and to someone she would never have had as a friend.
★ A son said he could handle it if his dad had died, and he could handle having a strange man in the house, but that the strange man was in his dad's body was more than he could take.

Relationships between all family members can change when the survivor demands a lot of time. Time spent on the survivor means that others in the family need to do more for themselves. This can be good or bad. Among children in families with a disabled child about half of siblings become more mature. They care more for others, are more independent and develop a strong sense of helping others. The other half becomes jealous and resentful. They say that they missed time with their parents. Couples with either a spouse or child survivor may also go either way. Some pull together stronger. Others fall apart entirely.

Time spent on the survivor means that others in the family need to do more for themselves. This can be good or bad.

Common Responses

The final piece in the changing family is how you have reacted. How have you felt? What do you experience? What has been your and your family's reaction to the changes? Use the ideas below to help you think about how you have been dealing with your new family. Make a list of your thoughts, feelings and reactions.

Effects of Changing Responsibilities, Roles and Relationships

Most people see very quickly that they have more to do now than before the injury or illness. What they might not notice right away is how their feelings have changed. If the change has led to more work and less help they might:

- ★ Resent the unfairness of it all,
- ★ Grow frustrated with trying to help the survivor regain skills,
- ★ Simmer or rage at others who don't understand,
- ★ Fear letting their family down, because they can't do it any more,
- ★ Wish it never happened or that the survivor had died,
- ★ As a parent, fear being a parent for the rest of their life,
- ★ If they are the parent of an adult, feel that they have been returned to a role they thought they left behind.

It is important to realize that these feelings are normal. They are part of adjusting to the new family.

Family members can also feel unappreciated. Many of the things they do go unnoticed. Many of the difficulties they face are unseen. Brain injury has been called the invisible injury. It is its invisibility that often leads others to underestimate what families have to do to manage.

Denial

Denial is a dirty word. No one wants to believe that they are in denial. But denial is normal. It is even healthy, in small doses. It is only when you don't deal with issues that can't be put aside that denial becomes a problem.

In brain injury, denial usually means that the family does not recognize problems. Once again, it is not clear that this is a bad thing. The family needs hope to go on. If denying some problems gives them that hope, then it is a good thing. Most health professionals see things this way. However, they do worry when denial leads the family or survivor to do something unsafe. It is at this point that denial may no longer be serving the survivor or the family.

For you, the reader, the question is, "Are you using a healthy dose of denial?"

Depression

Another common difficulty after brain injury is depression. It may be a feeling of "being down in the dumps." It may be more severe, including suicidal thoughts. Once again the message is that such feelings are normal. There is nothing to feel ashamed of. A brain injury is a very unusual situation. It can take amazing strength to cope with it. Sometimes your ability to cope is simply overwhelmed.

It is important, however, to know if and when you need help. The following are signs that you may need to seek help from a professional, like a counselor or your family doctor:

- ★ Do you find yourself crying uncontrollably for no reason?
- ★ Are you beginning to feel hopeless, like there is nothing you can do to make things better?
- ★ Do you find that you have lost interest in things that you used to enjoy?
- ★ Are you tired and listless?
- ★ Are you having trouble getting to sleep or waking up early and unable to get back to sleep?
- ★ Are you having thoughts of hurting yourself?

If you are experiencing many of these, especially thoughts of hurting yourself, you should see someone right away.

Coping Ideas

Look over what you have learned about changes in your family. Look over what you have written and ask yourself these questions:

- ★ Has there been much change?
- ★ Has that change led to good feelings, bad feelings or mixed feelings?
- ★ In what parts of my family's life have I seen change?
- ★ What parts of my family have led to strong changes in my feelings?

If the change has been enough to concern you, you might want to look at the following. Below are different results you might have found and coping strategies for each.

What you found:

Too many new responsibilities.

Suggestions for coping:

The key to coping here is to reduce demands on your time. You might try the following:

1. Simplify your life. Things are not going to pick up where they left off. Don't do anything you don't have to for a while.
2. Find out if you can buy help. Home Care, private companies and live in nannies or

housekeepers are some possibilities. There is usually some cost.

3. Pass some duties back to the survivor. Family members find themselves doing a lot for the survivor because they fear for his safety or dignity. Letting the survivor try things is the way to pass these duties back to him. Suggestions for how to do this can be found in the chapter called "Helping Rebuild Skills."

What you found:
New roles are overwhelming.
Suggestions for coping:
A lot of stress in roles comes from being responsible. The idea here is to let go of your role for a while to take the weight off your shoulders. Try the following:

1. Make time for fun or relaxation. It doesn't have to be a lot. It could be 15 minutes of listening to music, coffee with a friend, or an evening playing ball. The thing is to drop the load you are carrying for a little while and have fun.
2. Find a phrase to repeat to yourself when you feel overwhelmed. In Gone With the Wind, Scarlet O'Hara said, "I won't think about that today."
3. Take one day at a time. When you feel overwhelmed, take one hour at a time.

What you found:
New roles are upsetting the survivor.
Suggestions for coping:
You might try ignoring the problem (many families do.) Another way is to deal with it head on. You might try the following:

1. Develop a plan with the survivor to make decisions. Talk to the survivor about your worries and find out about his when making the plan. This way you deal with many hot issues directly rather than having them build up over time. You may want to have a professional involved when you do the planning.
2. Make roles for the survivor. Help him to find a new place in the family. Again a professional might help here.

What you found:
The survivor is like a new person.
Suggestions for coping:
This is a unique experience. It is often best dealt with by talking to others who understand. You might try the following:

1. Go to a brain injury support group. Sharing your experience with others who know firsthand what you are going through can be helpful.
2. Talk to a counselor who knows about brain injury. Talking to someone knowledgeable about such changes can

help you understand your feelings and make life decisions.

What you found:
You or the survivor appears depressed.
Suggestions for coping:
If you or the survivor have shown some of the more serious signs of depression you should see a professional. You can start with your family doctor. You might also try your local mental health centre or a private counselor.

What you found:
Denial is leading to difficulties in your home.
Suggestions for coping:
How to cope depends on who is in denial. If it is you, realizing the effects of denial is already making the first step. The rest usually comes with time. If it is the survivor, then you may want to take action.

1. Help the survivor to see what he can and cannot do. Use experiments to help him to get feedback (see "Helping Rebuild Skills.")
2. Help the survivor talk about changes that he has noticed. This can be very effective, though sometimes the help of a professional is needed.

What you found:
You are unsatisfied as a caregiver.
Suggestions for coping:
This is likely the most uncomfortable issue to deal with. This is because this situation is most likely to lead to separation or divorce. The following are possibilities:

1. Try to make a change in your thinking. If your choice is to stay, it is helpful to find a way of thinking that helps you feel better. For example, some see caregiving as a Christian duty or an honorable way to spend one's life.
2. Find someone to talk to about your feelings. This could be a counselor, a friend or a support group.
3. Look at other living arrangements. Sometimes the best choice for the family is to have their survivor live with someone else. For more information on your choices read the chapter "Residential Options."

What you found:
Some family members seem to be getting too little attention.
Suggestions for coping:
The idea here is to see if you can make time for yourself and your family. You might try the following:

1. Set up regular activities just for those family members. It should be a special time for you and them. However, it doesn't necessarily have to be. Some families have found that uncles, cousins, and family friends can sometimes provide this quality time.

2. Explore respite services in your health district. Respite is discussed in the chapter called "Residential Options."
3. Plan a family getaway. This may include leaving the survivor with someone else.

It is suggested above that one way to cope is to seek out a support group. The Saskatchewan Brain Injury Association (SBIA) helps to form such groups. You can phone them to find out about one in your area. If there isn't a local group, SBIA will help to start one up. Some health districts also have local Acquired Brain Injury Coordinators who run these groups. To find out more about them you can contact the ABI Partnership Project Services in your area (see the last chapter "Resources" for addresses.)

Separation, Divorce and Placing the Survivor Outside the Home

Leaving the survivor is a sensitive issue. Families have a lot of feelings in these situations. Guilt, because they should continue to help the survivor or because they have wished the survivor dead. Anger, because they feel health care professionals misled them into taking the survivor home or they didn't give enough support after they did return. Concern over how the choice to leave might affect the survivor and the rest of the family.

There is no right answer to the question, should the survivor live at home or somewhere else? There are not even some good rules of thumb, (though we know that the burden for the family increases as the survivor is less able to take care of himself.) Every family must decide for themselves. All we can hope to do here is to tell you that it is a choice. Others have made it. Some have regretted the choice. Others have felt that their choice was the best thing to have done for their families.

The New Lifestyle

The New Lifestyle

Each family responds to the changes brought about by the brain injury in its own way and at its own pace. Your family may learn to see the changes as positive, however stressful to undergo, or you may struggle with them for a long time. There is no right or wrong way to feel when it comes to establishing a new life for your family. It is a long process. It is also complicated by the fact that you cannot accurately predict what abilities your loved one will eventually have, instead, you will be making adjustments throughout the different stages of recovery.

★ One of the most helpful things you can do is allow yourself to grieve your family's losses. As your grief is expressed, it will become easier to move forward and establish a new life.

Energy Levels

Initially, fatigue will be a factor in establishing a new lifestyle. The survivor will not have the energy to maintain a busy lifestyle. While he may or may not regain his pre-injury level of activity, his overall energy level will gradually increase. Gradually is the key word. On a daily basis, it may seem that little is changing, but over the long term you will see a steady increase in the survivor's energy level.

Social Skills

Social skills are essential to maintaining friendships, yet they may be affected by the brain injury. The survivor may have difficulty making eye contact, dominate the conversation, or say the same thing every time he sees someone. He may not respect personal space and stand or sit too close, or he may be very rude. Some survivors have difficulty showing emotion, causing their general expression to remain the same whether hearing happy or sad news.

Other commonly seen behaviours that affect social skills include impulsiveness, distractibility, inability to read subtle non-verbal behaviour, and decreased sensitivity to other people's needs or social

There is no right or wrong way to feel when it comes to establishing a new life for your family.

situations. A survivor may have acceptable social skills but lack the memory or capacity for abstract thinking needed to participate in social activities.

Children are perhaps most distressed by a parent's lack of social skills. Pre-teens and early teens, in particular, are easily embarrassed by their parents at any time and often find a parent demonstrating the preceding behaviours very embarrassing.

- ★ Friends can be told your parent is not the same since the injury. Strangers who stare can be ignored, although this may be difficult to do.

It is important for your family to provide non-judgmental feedback regarding appropriate and inappropriate social behaviours. Practice various social situations with the survivor to help him learn appropriate behaviour. Since he may have impaired memory, as well as difficulty applying learning from one situation to another, be prepared to repeat the lessons. With repetition and coaching, some survivors regain their social skills.

Building a New Social Life for the Survivor

When the survivor first returns home, a lot of energy will be spent adjusting to the new situation. At this point, it is important not to set the stage for a restricted social life. This applies to everyone in the family. Because the survivor may not have the physical and intellectual skills needed to maintain his previous social life, you will need to be creative in your efforts to build a new one.

- ★ Offer safe social activities rather than allowing the survivor to choose without direction. His judgment may be impaired and could lead him into unsafe situations. Your role is to encourage him to take risks within reason so he can gradually gain confidence in social situations.
- ★ Start the socialization process with a few people, in a familiar setting, doing a quiet activity. As the survivor gains energy, he will be less fatigued and less easily distracted. You can then increase the complexity of social situations.
- ★ Learn from past events. If a situation does not go well, analyze it. What happened? How was it set up? Was there anything you could have changed to make it easier? Be positive - wisdom comes from experience, and experience comes from making mistakes.

Establishing New Friendships

Spending time with friends is one of the most rewarding

parts of life, yet changes caused by a brain injury often cause old friends to drift away. They may not understand the survivor's changed behaviour or may not accept the changes.

If the survivor's friends are drifting away, make every effort to find new ones. A good way to start is by finding activities the survivor can participate in and enjoys doing. Leisure activities, and volunteer work provide social settings where common interests may be discovered. Shared interests are the basis of new friendships. Loss of friends is especially devastating for children and adolescents. Unfortunately, it is a common experience for young people with any type of disability. There are no easy answers, but there are things you can do.

- ★ Concentrate on the abilities your child has and use that to foster new friendships based on common interests.
- ★ Emphasize abilities and do not be discouraged by the initial reaction of others.
- ★ Provide your child with opportunities to interact with his peers just as you would any other child.
- ★ Engage your child in activities they enjoy. If you need an extra pair of hands to enable them to participate, ask local church groups, Guides and Scouts, or mentor programs. For more suggestions, contact one of the provincial programs for children with disabilities or talk to your child's school.
- ★ Look to your extended family. Your child's deepest friendships may be with cousins, aunts, uncles or grandparents.

In your efforts to build new friendships for your survivor, concentrate on developing quality rather than quantity in relationships.

Staying Active

Since many people do not return to work, or work less than full time, following a brain injury, it is important to find meaningful activity. Changes in the survivor's abilities, such as diminished social skills, can make this a challenge. Your family can be of immeasurable help to the survivor by providing coaching, feedback and instruction. There are also outside resources available, such as the Provincial Acquired Brain Injury Services. Do not hesitate to seek assistance.

Recreation and Leisure

The brain injury may affect what the survivor does for fun. For example, fatigue may affect his ability to participate in leisure

activities, while diminished social skills may affect his ability to enjoy these activities with others.

- ★ Be open to participating in new ways. For example, if the survivor enjoyed curling before the injury but is no longer able to curl, consider involving him as a spectator or volunteer.
- ★ Modify a previous activity to fit his current abilities. For example, if the survivor loved playing cards but now has memory and concentration problems, look for card games where chance is more important than memory. One spouse says that she and her husband "play" a lot more now, something that would not have happened prior to the brain injury.
- ★ Find a "leisure buddy" to accompany the survivor to various activities. In addition to helping the survivor develop self confidence, a leisure buddy can give you a few hours respite.

If you need guidance, contact the provincial ABI services in your area (listings start on page 83) and ask them to direct you to a recreational therapist. If you live in a larger community, call the municipal recreation and/or leisure services department and ask about services and facilities in your area.

Volunteering

Once the survivor is physically able to do more, it may be helpful to engage him in volunteer activities. Volunteering will give him a chance to do something for others, and it can boost his self esteem. Check out the volunteer opportunities in your community.

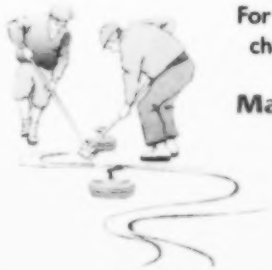
- ★ Look for activities that match the survivor's activity level and social skills.

Return to Work

Since it is not possible to predict with accuracy who will eventually return to work, survivors need to work on regaining as many skills as possible. Social skills and energy levels, for example, are critical to a successful return to work.

- ★ Develop a daily schedule that includes meaningful activities (such as leisure and volunteering) as well as activities designed to help the survivor practice and improve his skills. A daily routine can help the survivor in his recovery process (by providing structure to his day.)

For a more information, refer to the chapter on Return to Work.



Maintaining Your Family's Social Life

It is important for family members to maintain social

contact with others. If you are the caregiving spouse:

- ★ Do not quit your job unless absolutely necessary,
- ★ Balance your need to talk about the stress of your situation with your need to talk about other things,
- ★ Schedule social activities for yourself and follow through,
- ★ Arrange for respite care to give yourself a rest (see Residential Options chapter.)

It is also important for you to maintain friendships for yourself. Studies have consistently shown that people with strong social networks manage stress much better. If couple and other friendships disappear, establish new ones by participating in one or two social interests or hobbies, or joining a support group for families of survivors of brain injury.

Driving

Saskatchewan law requires that if you have a condition likely to affect your ability to drive you must notify the insurer. Since a brain injury is likely to affect a survivor's ability to drive, they are required to report the situation to SGI. Saskatchewan law has given SGI the mandate to determine who may drive.

On discharge from hospital, the doctor responsible for the survivor's care most often advises the family on whether or not it is safe for the survivor to drive. In either case, SGI must be notified.

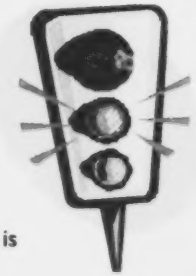
To notify SGI, obtain a Supplementary Medical Application Form from any driver's license issuer, fill it out and send it to SGI. SGI will send you a form that your family doctor needs to fill out. They will then review the information from your doctor and determine whether the survivor may drive.

- ★ When leaving the hospital, if the survivor is advised by the doctor that it is safe to drive, it is legal for him to continue driving until SGI makes a determination.

On discharge from hospital, many survivors of brain injury should not be driving. Reflexes are slow, decision-making is slow, and judgment is impaired. These changes, however, may be subtle. It is not uncommon for them to go unnoticed at first, by the family and the doctor. In fact, it may take time to realize the survivor should not be driving, or should only drive in restricted situations such as light traffic or rural settings.

Because you deal with the survivor on a daily basis, you may realize it is unsafe for him to drive while your family physician persists in believing it is safe. This can be stressful if you are advocating to have the survivor's license removed against his wishes and those of other less involved family members. In this case, a driver evaluation may prove useful.

★ You may refer the survivor to the Driver Evaluation Program at Saskatoon City Hospital, or have the family physician or other health professional refer them. The referral will be reviewed by program staff, who will determine if an assessment is appropriate. There is a charge which may be covered by a third party such as SGI, but you may have to pay it yourself. The telephone number of the Driver Evaluation Program is (306)655-8612.



For many survivors, losing their driver's license is a major blow to independence, especially if they live in a rural area. You and the survivor may need support to work through the process. Get in touch with ABI Partnership Project Services or other health professionals in your area, or talk to other families of survivors.

Resources

Brain Injury: A Guide for Families
2nd ed., HDI Coping Series, number 1
HDI Publishers, Houston, Texas, 1996

An easy to read book that suggests solutions to common survivor and family behaviours.

When a Parent has a Brain Injury: Sons and Daughters Speak Out
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An excellent resource in which children of survivors share their experiences.

Return To Work

Return to Work

Work is important to all of us. It brings in money to pay the bills. It helps us feel we have a place in our world. It lets us do something meaningful. It is not surprising that many survivors want to return to work as soon as they can.

For families, this desire to work can raise many questions. The first is usually:

★ How do you know when the survivor is ready to go back?

Families also want to know:

★ What is the best way to return to work?
★ What help will the survivor need when he returns?
★ Whom can they get help from?
★ What happens if the return to work is unsuccessful?

Signs of Readiness

In general, the survivor is ready to return to work when you see the following:

★ The survivor has enough energy to work at least a half day.
★ The survivor can carry a conversation, knows how to act towards others, and can pick up important social cues (like when a person is upset.)
★ He can plan and follow through on simple things.
★ He uses aids, like a diary, when necessary.

Some professionals who help survivors return to work might add the following:

★ The survivor must be able to control his temper.
★ He must be able to recognize his own mistakes.
★ The survivor must be able to initiate work on his own.

Returning To the Old Job

When a survivor tries to return to work his old job is often considered first. This is most likely to happen when:

★ The survivor had been in the old job a long time and knew it well.
★ The survivor's insurance plan states that he must try to return to his old job first.
★ The last employer is committed to the survivor.
★ The survivor has problems with new learning.

Returning to his last job means the survivor does not have as much to learn.

The last point is important because for many survivors learning new information is difficult. Returning to his last job means the survivor does not have as much to learn.

Even when returning to an old job there are many things to consider. How many hours a day should the survivor work at the start? Do work hours need to be changed? Should the survivor begin with only some tasks? Which tasks should those be? Do there need to be changes to the workplace, or to the survivor's work station?

The following is generally recommended:

- ★ Gradually return to work. Begin with a few hours a day or week and slowly increase the work time over weeks or even months.
- ★ Gradually phase in different job tasks. The survivor should start with the simplest and most frequent ones and build to the more complicated and uncommon ones.
- ★ Change job demands to help the survivor cope with disabilities. Noise levels and distractions may need to be kept to a minimum. The timing of work may need to be changed. If the person is better able to complete some tasks when rested, those tasks may need to be done at the beginning of the day.
- ★ Use devices like memory books, earplugs and canes. Let the survivor know how these can help with the work.

Sometimes the return to the old job does not work out. This is most likely to happen where advanced work skills are needed or where the costs of mistakes are high. For example, a surgeon is less likely to successfully return to work than a janitor. The surgeon needs to remember lots of facts about people's health. He also must make good decisions when doing surgery. The costs of a mistake in his work could be a person's life. The janitor needs to know what he has to clean and how to do it. He does not make life and death decisions. If he makes a mistake, there is little chance of harm to others.

The employer may be willing to try the survivor in another job, where the old job doesn't work out. If this happens, it is important to look for a new job that fits with the survivor's strengths.

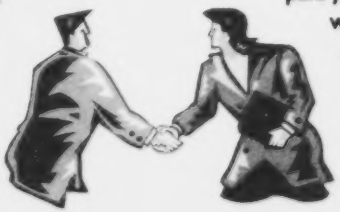
Use of an occupational therapist or vocational counselor to help set up the return to work is usually recommended. Such a person can prepare the work place, anticipate problems and help negotiate the return to work. As well, there are often tests and interviews to decide how ready the survivor is for his return. These will be discussed more below.

Looking For a New Job

There are many reasons why a survivor might choose to look for a new job. These reasons include:

- ★ Failure of the return to the old job,
- ★ Loss of key work skills that don't allow return to the old job (e.g., an office manager who is no longer able to plan out how to get the work done,)
- ★ Loss of the old job (e.g., when absence from work leads to replacement,)
- ★ No old job to return to.

To find a new job a series of steps is likely to be followed. These steps help professionals decide what the survivor needs in a job and predict how successful he might be. They might also happen in a return to the old job, but are more likely when a new job is sought. The steps can include the following:



- ★ A vocational assessment. This usually involves testing to find the survivor's job skills and interests. It may also include short job placements.
- ★ A neuropsychological assessment. The tests used in this assessment measure the survivor's thinking ability. This includes abilities like memory and attention.
- ★ Job skills training. Some places offer training in job skills needed for any workplace. This includes skills like being on time, being respectful, dressing correctly and learning one's job.
- ★ School or retraining. Before starting a new job it is sometimes necessary to get further education. This education usually teaches the survivor how to do a job that he has never done before.
- ★ A job try-out. Many survivors have trouble taking what they have learned in one place and using it in another. For these survivors it doesn't make sense to learn about a job in the classroom. They need to learn on the job. The job try-out also shows whether the survivor works fast enough and well enough to get a paid job, as well as whether they would enjoy the work. Finally, the try-out can reveal how much support the survivor may need to get or keep a job.
- ★ A job search. A job search involves writing a resume,

looking for jobs, speaking with employers, applying for jobs and going to interviews. SEARCHs is a program that helps with these kinds of things. (See the end of this chapter for information on SEARCHs.)

The steps taken by the survivor will vary. Some will only need help with the job search. Others will need all of the above. Many survivors will need something in between. The amount and type of help needed is usually decided based on testing, the survivor's wishes and results of job try-outs or education.

Most survivors will need some help. A vocational rehabilitation counselor or an occupational therapist is usually the best support. These professionals can be of most help if they know about:

- ★ Brain injuries,
- ★ The job market,
- ★ Where persons with disabilities can get a job.

Many people will also need a job coach. A job coach spends time helping the survivor learn the job. They also help the survivor to see how well he is doing on the job and how well he is getting along with others. The job coach may work alongside the survivor for some time. This usually happens where there are deadlines or work quotas. This support may continue until the survivor can work fast enough on his own.

If the job try-out works the survivor has a job. Sometimes it is necessary to try work in several places. The plan may be to try out several jobs as part of the assessment to see what sort of work would be best for the survivor. Job try-outs can also give the survivor important work skills. Getting to work on time and listening to the boss are some of these skills.

Keeping the Job

Finding a job is easier for survivors than keeping a job. The most common reasons for losing a job are:

- ★ Poor conduct (e.g., temper problems, social problems,)
- ★ Poor attendance (coming late too often or missing work,)
- ★ High levels of distress in the survivor.

Having someone like a job coach can sometimes keep these problems from becoming a lost job. The job coach can increase the survivor's awareness and help bring about change. They can also educate

the survivor, his co-workers and the employer. Long-term follow-up is also important. Often there is a honeymoon period when the survivor starts work. Co-workers and employers put up with poor conduct, rather than talk about the problem. Then one day they get fed up and fire the person. Follow-up has to be long enough to cover this possibility.

There are no guarantees of staying in a job, but specialists tell us that there are some things that are more likely to lead to success. The most important is social skill. Social skill is the ability to get along with others. Talking with others, knowing whether they are happy, sad or mad, and treating them with respect are all social skills.

Other qualities that help survivors to get and keep a job include:

- ★ Having well defined job interests and abilities,
- ★ Being assertive rather than aggressive,
- ★ Being able to move about well and having good vision,
- ★ Being able to work on their own for a long time,
- ★ Using strategies to help with problems like memory,
- ★ Having their interests and abilities considered in choosing the job,
- ★ Having the chance to decide that they like the job.

Expectations

Expectations are what we hope will happen. Realistic expectations are those hopes that are most likely to happen. For a person to have these he needs to know what usually happens in his situation.

Return to work after a moderate to severe brain injury isn't easy. In those who needed help to return to work, studies show only 1 in 2 were still employed at the end of a year. Of those who were employed, only half were in the same job that they started at the beginning of the year. A different study showed that if the survivor wasn't back to work in six months he likely would never return.

Another thing we know is that the survivor's chance of keeping a job is higher if he was

Finding a job is easier for survivors than keeping a job.

highly trained or experienced before the injury or illness. This does not mean that the survivors returned to their old work. Most returned to jobs that required much less training or skills. In fact, survivors have been most successful at keeping what are called entry-level jobs. Examples would be janitor, file clerk or dishwasher.

These studies tell us that many survivors may never return successfully to the work place. They also tell us that those who do usually go back to a job with less money and status. Both of these situations can be hard for the survivor to adjust to.

It is important to know that there can be other difficulties even where return to work is successful. Sometimes families believe that things will get better once the survivor has a job. This is not always the case. It is important to remember that starting a new job is always stressful, and more so for someone with a brain injury. The survivor will be more fatigued. He will be learning a new job or relearning an old one. He will be interacting with more people. The survivor may also have to cope with fears of failing. You and the survivor need to be prepared for the possibility that the job will make things tougher at home. There is also some evidence that substance abuse problems are greater after the survivor returns to work. Support from family and friends is very important through this stressful time.

Resources

Printed Publications

i.e. Magazine
Volume 4, Issue 1, 1996

A publication of the Ontario Brain Injury Association
Helpful articles in this issue include:

Obtaining Real World Success in Rejoining the Workforce
Hamish Godfrey, Ph.D.
Department of Psychology, University of Otago, Dunedin, New Zealand

Supported Employment as an Option for Return to Competitive Employment
Jeffrey Kreutzer, Ph.D. and Adrienne Witol, Ph.D.
Department of Physical Medicine and Rehabilitation, Medical College of Virginia, Richmond, VA

Rejoining the Workforce: There are No Simple Solutions
Robert Fraser, Ph.D.
Harborview Medical Centre, Seattle, WA

Unemployment Rates Among Individuals with Brain Injury
Barry Willer, Ph.D.
Professor, State University of New York at Buffalo
Director of Training, Ontario Brain Injury Association

Returning to Employment
Ellen Boelcke and Jill Howell
WIT Works, Central Okanagan Head Injury Society, Kelowna, BC

Working After Brain Injury: What Can I Do?
Dana DeBoskey, Editor, 1996

Hiring the Head Injured: What to Expect
by DeBoskey, Benyo, Calub, Oleson, Morin
HDI Coping Series, number 3, 1989

Head Injury Rehabilitation: Developing Adaptive Work Behaviours
Frank Lewis
HDI Professional Series on Traumatic Brain Injury, no. 17, 1988

The preceding 3 booklets are all published by HDI Publishers. They are easy to read and provide greater detail on some of the general issues discussed in this section. They can be obtained by contacting HDI, borrowing them through an interlibrary loan from your local library, or from any ABI Outreach Team.

HDI Publishers
P.O. Box 131401
Houston, TX 77219-1401
Toll Free: 1-800-321-7037 Tel: (713) 682-8700 Fax (713) 956-2288

Saskatchewan-Based Resources
Any ABI Outreach Team can provide some assistance. Call to find out what services are available.

The following are specific job related programs available in Saskatchewan at the time of printing. Contact these programs directly for more information.

Career Headways, Inc.
1919 Broad St., Regina, SK S4P 2Z6
Tel: (306) 352-8768

The survivor should be capable of some two-way communication, be medically stable, demonstrate a potential for improvement, make a commitment to the program, and be willing to undergo an assessment and interview process. Participants work on the following areas: thinking, behaviour, perception and speech skills, social, recreational and vocational skills.

Saskatchewan Abilities Council, Supported Employment Services
1410 Kilburn Ave., Saskatoon, SK S7M 0J8
Tel: (306) 653-8886

Saskatchewan Abilities Council (in Regina)
825 McDonald St., Regina, SK S4N 2X5
Tel: (306) 569-9048

To participate in these programs, survivors must be able to function independently in terms of personal care, demonstrate a willingness to participate, be capable of some two-way communication, have completed a vocational assessment, have established realistic vocational goals including at least two occupational choices, have a family physician, and be medically stable.

Radius Community Centre for Education & Employment Training
#200-245 3rd Ave. S., Saskatoon, SK S7K 1M4
Tel: (306) 665-0362

This program works with children and youth to re-integrate them into age appropriate activities within their community. They will provide consultation for persons residing in and around Saskatoon.

SEARCHs, Saskatoon Employment Access Resource Centre for Human Services
505 - 23rd Street East, Saskatoon, SK S7K 4K7
Tel: (306) 343-3463 Fax: (306) 343-3460

SEARCHs serves Saskatoon and a surrounding area bordered by Rosthern to the north, Beechy to the south, Kindersley to the west and Quill Lake to the east. They provide a range of services to enhance the employability of persons with any type of disability. SEARCHs markets persons with appropriate skills to employers. A partnership of 24 community-based organizations forms the foundation of SEARCHs. Survivors can be referred to the program by any one of those organizations or an employer, or they can refer themselves.

South Saskatchewan Independant Living Centre
2240 Albert Street, Regina, SK S4P 2V2
Tel: (306) 757-7452 Fax: (306) 757-5892
email: ssilc@sk.sympatico.ca

Provides a variety of supports to persons with disabilities including work related issues.

North Saskatchewan Independent Living Centre
112 514 23rd Street East, Saskatoon, SK S7K 0J8
Tel: (306) 665-5508 Fax (306) 244-2453
email: nsilc@dlcwest.com website: www.dlcwest.com/~nsilc.

This agency is the northern counterpart of the South Saskatchewan Independent Living Centre and provides similar services to persons with a variety of disabilities who live in the northern half of the province.

Notes

Return To School

Return to School

In the case of a child with a brain injury, both the family and the child may be eager for the survivor to return to school. There are resources available to assist in this transition.

- ★ Education System. Most school boards provide similar services, so your child does not necessarily have to attend a certain school. The manner in which schools provide services, however, may vary.
- ★ Provincial ABI Resources. The ABI outreach teams and the ABI coordinators can be of assistance when your child returns to school. These professionals can provide education on brain injury to your school, consult with teachers and provide a link to the hospital and other medical services.
- ★ Health Professionals. In Saskatchewan, the health professionals most likely to be involved with your child's return to school are psychologists, speech language pathologists and occupational therapists.

ABI Services, health professionals and the education system work as a team with the family and child.

What to Expect from Your Child

The following changes may affect your child's return to school. This is not an exhaustive list - your child may experience many of these changes or none at all.

- ★ Fatigue,
- ★ Irritability, angry outbursts, and impulsiveness,
- ★ Passive behaviour,
- ★ Depression,
- ★ Forgetfulness,
- ★ Poor organizational skills,
- ★ Difficulty following directions,
- ★ Immature behaviour,
- ★ Inappropriate sexual behaviour.

Fatigue

Fatigue is the most common problem in a return to school. School is a highly stimulating environment, and at first it will be difficult for your child to deal with all the noise and activity. This is why many children return to school gradually.

Your child may start by attending a few hours, without educational demands, two or three days a week. As he gains energy, attendance is gradually increased and a

Many children return to school gradually - a few hours a week at first. As your child gains energy, he may slowly build up to full days.

curriculum started. Eventually, your child may attend full days, five days a week.

In rural areas, transportation limitations may mean your child is at school for longer periods. To prevent fatigue, you may need to arrange for the school to give your child rest periods in a quiet place. Remember, it is important that your child participate in school activities only when he has the mental and physical energy to do so.

Irritability and Angry Outbursts
Irritability and angry outbursts are also common among children learning how to deal with the stimulation of school. Look at what precedes the behaviour. Do you notice a pattern? Is there something you can change, such as introducing a rest period, that will help prevent or reduce the frequency of the behaviour?

Immature or Inappropriate Behaviour
Immature or inappropriate behaviours may also cause problems. Immature behaviours include interrupting frequently, making tactless remarks, displaying messy eating habits, or repeating words over and over. Inappropriate behaviours may include sexual comments, gestures or actions that are out of context. Books listed at the end of this chapter provide helpful information on coping with these and other behaviours.

Your Role as Parents

Carry-over and consistency between home and school gives your child the best chance for recovery. As parents, you are the constant in your child's life, the mainstay in changing school and health care environments. Your perspective and input are therefore vital. Talk to your child's teachers about what your child was like prior to the injury and what he is like now, and share what you have learned in promoting acceptable behaviour and helping your child achieve his highest potential.

Working with the School

This section was prepared with input from officials from a variety of school boards. In certain circumstances, school boards will

provide education up to the semester in which the pupil turns twenty-two years old.

Almost all children with brain injuries will return to school. Your school, however, may have had few, if any, children with brain injuries. The more you can assist the school, the better it will be for your child. This does not mean the onus is on you: each school board has someone responsible for services to students with special needs (the usual title pertains to "pupil services") and access to a variety of information and resources.

About Teachers

The classroom teacher and resource room teacher will be most involved with your child. Although many teachers do not have specific training working with students with brain injury, many of the adaptive strategies and teaching techniques used are familiar to them. Interest, flexibility and commitment to learn about brain injury are often hallmarks of an effective teacher. The classroom teacher is not an expert in special needs situations; the resource room teacher has more knowledge in this area. The classroom and resource room teachers will work together to create a program for your child.

Getting Started

- ★ Contact the principal of your local school, or the school you want your child to attend, as soon as possible after the injury. This will give the school time to prepare.
- ★ Arrange a meeting with the principal, classroom teacher and resource room teacher. It may or may not be appropriate for your child to attend. You may also bring a "support" person - a friend, family member or health professional. The purpose of the meeting is to give the school enough information to develop a teaching plan for your child.
- ★ Prepare for the meeting by writing down your short and long term goals - what do you want for your child? What are his strengths, etc.? Remember to write down - and ask - any questions you have.
- ★ Bring background information to the

As parents, you have the most intimate knowledge of your child. Share your insights with the school. What was your child like before the injury? What interventions work best in promoting acceptable behaviour?

meeting. For example, if you have reports that identify your child's areas of ability and difficulty, bring copies to the meeting. More important, bring names and contact numbers of health professionals who can help the school develop an appropriate program. The more information you can give the school, the better program they can design.

"Disabled Pupil"

After the first formal meeting, the school - with your permission - will collect information about your child. Based on this information they may seek to have your child designated a "disabled pupil." The Education Act provides for such a designation.

★ It is often to your advantage to have your child designated a "disabled pupil" because it allows funding for additional services such as a teacher associate, tutoring, special equipment and summer programming.

Remember, while it is important for your child to have all the services he needs, it is equally important not to think of more services as better service. Think about what your child needs and look for services that best meet those needs.

The Teaching Plan

A second meeting is needed to discuss the plan for teaching your child. The plan may be referred to as a Personal Program Plan (PPP), Individualized Program Plan (IPP), or Individualized Education Plan (IEP). If you do not hear from the school, call and initiate the meeting yourself. It is important that you have an opportunity to discuss the teaching plan with everyone working with your child.

★ Ask for a copy of the plan prior to the meeting. Read it ahead of time. Write down your questions and concerns.

The teaching plan is not meant to be set in stone. Instead, it should have regular review times built into it. It may be helpful to set actual meeting dates for these reviews, but do not hesitate to call your child's teacher at any time.

Reviews will evaluate how well the plan is working in relation to your child's emotional

**Quality of service is more important than quantity.
Instead of looking for more services, look for specific services
that can help your child realize his full potential.**

adjustment, functional skills and available peer support. Over time, long range goals may change as your child's abilities become more clear. Formal plans can be made to help prepare your child for expected developments such as a change in teachers, grades, even schools. Ongoing discussions between yourself and the school, and possibly health professionals, will ensure pertinent changes are made.

Consulting a Specialist

It may be helpful for you and your child to have a consultation with a neuropsychologist. Neuropsychologists have advanced training in the relationship between brain function and behaviour. Standard psychological tests tend to provide information on past learning, whereas children with brain injuries have problems learning now. The tests used by neuropsychologists provide information on your child's ability to learn, communicate, plan, organize and relate to others. Such an assessment can provide critical information for building effective and efficient educational plans.

★ Talk to a health professional, a member of the ABI Outreach Team or an ABI coordinator about whether your child could benefit from a consultation with a neuropyschologist.

Handling Disagreements with the School

Children benefit most when parents and school operate as partners. Because it is in people's nature to see things from different points of view, there may be disagreements.

What to Do When You Disagree

★ First and most important, convey your disagreement to the school calmly. Many disagreements are easily and quickly resolved. For example, you may have information the school does not, simply giving them that information may resolve the issue. Or there may have been a misunderstanding and discussing it with the appropriate person may resolve the issue.

★ In most cases, solving problems informally works better than formal appeals. Start by talking to the person closest to the situation, usually the classroom teacher. Outline what you are unhappy about and why. Explain how you would like the situation changed.

★ If you are unable to resolve the problem, talk to the principal. If you are still unable to resolve the issue, contact the local school board and talk to the person responsible for student services or the Director of Education for the Board.

★ The next step is to take your concerns to

the Department of Education, which has regional superintendents for special education. It is unlikely you will need to go this far - most disagreements are resolved with the classroom teacher.

★ Remember, disagreements can be an opportunity for more in-depth problem solving ... and that can lead to improvements for your child.

What to Do When You're Angry

When people relate to each other angrily, more heat than light is generated. We all know that, but when it is your child, that truism is not always easy to remember. Here are some guidelines for dealing with situations that make you angry.

★ Always respond with well thought out arguments. These will take you time to develop, and that time will help temper your anger.

★ Remember that staff at the school are decent, ordinary people trying to allocate limited resources to best meet the needs of hundreds of children. Your job is your child. Their job is much broader.

★ If you find yourself getting angry in a meeting, ask for a recess. If necessary, ask to resume the meeting another day.

★ A disagreement does not mean you have to be angry. Simply state on what point you disagree and why. You will be a stronger advocate for your child if you present yourself in a credible, professional manner.

The Importance of Early Intervention for Young Children

Many people assume that an injury in a very young child is less serious than in an older child or adult because of the remarkable recuperative abilities of young children. This may apply to physical problems, but unfortunately for intellectual tasks such as thinking, problem solving and planning, an early injury may be more serious. This makes early intervention by professionals very important.

★ Children lack the years of learning of older people. An older child or adult can often compensate for learning difficulties by building on past knowledge, whereas a young child has not had the opportunity to lay that foundation.

★ The nature of a brain injury can also make learning more difficult as time goes by. For example, young children do not think abstractly so any deficiency in this area goes unnoticed until the age when abstract thinking is expected. Due to the brain injury, the child suddenly lags behind his peers.

Grief, Guilt & Depression

Many parents whose children have an acquired brain injury experience grief, guilt and/or depression at what has been lost. These are normal emotional responses. You need to grieve your losses, and depending on his age, so may your child. You may feel guilt over the occurrence of the injury, even if it could not reasonably have been prevented. Guilt is often expressed as anger and blame directed at others. Depression is another common response. If you or your child are finding it difficult to move through these emotions, contact your local school board or ABI Outreach Team and ask about counseling.

Resources

Teaching Persons with a Brain Injury: What to Expect
2nd edition, HDI Coping Series, number 5.
Produced by Tampa General Rehabilitation Center, Tampa General Hospital, Tampa, Florida.
HDI Publishers, Houston, Texas, 1996

A quick read with listings of common difficulties encountered by students with brain injuries and their teachers. Includes possible solutions.

Signs and Strategies for Educating Students with Brain Injuries: A Practical Guide for Teachers and Schools
Gary Wolcott, Marilyn Lash, Sue Pearson. HDI Publishers, Houston, Texas, 1995.

Easy-to-read handbook with practical advice and examples for parents and teachers, including classroom strategies and information sheets for teachers.

Traumatic Brain Injury in Children & Teens
A Guide for Families Developed by New Hampshire Emergency Medical Services for Children Project.
Dartmouth Medical School, 7280 Butler, Hanover, NH 03755
Tel: (603) 650-1813

This comprehensive manual includes information from intensive care to return to school. There are excellent chapters on behaviours and return to school. The book is written for a New Hampshire audience, so not all information will apply.

Residential Options

Residential Options

Deciding where the survivor should live is a major decision, both for your family and the survivor. The age of the survivor, severity of injury, and family resources will all influence your decision.

Possible Options

The survivor may:

- ★ Live independently,
- ★ Live independently with informal support from the family,
- ★ Live independently with formal support from an agency such as Home Care or a private agency,
- ★ Live in a transitional setting,
- ★ Live in an institutional setting (see resource list at end of chapter.)

The family of the survivor may:

- ★ Provide all care,
- ★ Provide care with informal help from the extended family and friends,
- ★ Provide care with formal help from an outside agency,
- ★ Provide care with informal or formal arrangements for respite.

Respite gives you a rest from caregiving duties. Informal arrangements may include having another family member provide care or having the person go to someone else's home for a period of time. Formal respite may range from having someone from Home Care or a private agency come in a few hours a week, to having the survivor spend several weeks at a group home, personal care home, or special care home.

Identify Local Resources

To identify available residential options and resources in your area, ask the health professionals working with you and the survivor for a referral to an agency such as Home Care. You can also find Home Care listed in your local telephone book or by calling your local Health District office. Home Care coordinators in your area will know what services are available through your Health District and through private agencies.

Private agencies may offer nursing care, personal care, homemaking help, supervision, or companionship. Check your insurance policies to see if any of these services are covered, especially if these services are not provided by Home Care.

Age Plays a Role in Your Decision

The age of the survivor plays a significant role in your consideration of residential options.

- ★ Small children almost always go home, even with very severe brain injuries. Because of their small size, the family is more capable of providing the physical care needed. More importantly, many feel a family setting provides the best environment in which to help the child reach maximum potential. As the child grows, the family's capabilities grow as well, allowing them to adapt and make plans for the future.
- ★ Older children and adolescents usually go home, especially if they do not require heavy physical care. Home and school become the rehabilitation environment and allow for as normal a life as possible.
- ★ For a young adult who had been living independently, the decision is more complicated. Depending on abilities, it may not be safe for him to continue living independently. If the decision is made to move back to the parental home, however, adjustments need to be made. Older parents may be unable to provide the supervision needed, or the young adult may resist parental authority and supervision.
- ★ For an adult with children, residential options must consider the needs of everyone in the family unit.
- ★ For an elderly adult with a spouse, the physical and mental ability of the spouse to provide the required level of care must be considered.

Every family is different. The decision you make must be the one that works best for you.

Keep Your Options Open

It is not uncommon to try several residential options in the first few years. As the survivor goes through the stages of recovery, your family will discover the extent of your caregiving capabilities. Your first decision may not be the permanent solution. Some survivors may move to progressively more independent living arrangements; some families may need more and more assistance

The first option you try may not be the permanent solution. Some survivors progress to more independent living; some families realize they need more assistance.

It is normal to feel overwhelmed by the needs of the person with the brain injury.

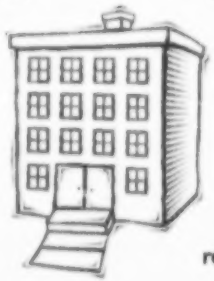
as they exhaust their own physical and mental resources.

Feeling Overwhelmed

It is normal to feel overwhelmed by the needs of the survivor, but this alone does not mean your family member should not live at home. Discuss your feelings with the health professionals working with you. They are familiar with the emotions you are going through. Talking to them will help you realize the burden of care is not yours alone. In fact, it may lead you to discover more workable living arrangements.

A Home Away from Home

There may come a time when your family decides it is best for the survivor to live in a more structured setting. The first step in this process is to contact your local Health District office. They will put you in touch with the department responsible for arranging such placements. In most cases this is Home Care, although your Health District may be different.



The most common places are group homes, personal care homes and special care homes. Your Home Care or other contact will discuss the options available in your area, as well as any waiting lists.

- ★ Visit the places you think are suitable.
- ★ Talk to staff and ask questions.
- ★ If someone you know has a family member living there, ask their opinion.
- ★ Visit a variety of homes - it may help you feel more comfortable with your decision.

There are currently very few institutional options designed for persons with a brain injury. It is a recognized area of need, however, and more options will hopefully become available over time.

Coping with Guilt

Placing a family member in an institutional setting can be extremely stressful, and it is not uncommon to experience guilt. Your decision does not mean you are abandoning the survivor. Given the needs of your whole family, it may be the only real option. You can remain active in the life of the survivor

through regular visits and home passes. You may even find your time together is of higher quality.

Discuss your feelings with the Home Care coordinator or the social worker in the survivor's new home. Talk to friends who have had to make the same decision, or get in touch with a local brain injury support group. To see if there is one in your area, call the Saskatchewan Brain Injury Association at (306) 373-1555.

Resources

"Selecting a Personal Care Home"
A pamphlet from Saskatchewan Health that outlines how to choose the right personal care home for your situation. Available through Home Care offices.

The following programs are specifically designed for survivors of brain injury.

Phoenix Residential Society
1770 Halifax Street, Regina, SK S4N 7K3
Tel: (306) 569-1977 Fax: (306) 569-1986

An 8 suite apartment block staffed on a 24 hour basis. Incorporates respite and crisis accommodation. Also provides support services to 10-12 individuals who live in a home of their choice and do not require 24 hour support.

Residential Options Program
Pineland Home Care
196-9th St. East, Prince Albert, SK S6V 0X5
Tel: (306) 922-2969 Fax: (306) 763-4472

Provides support in finding and maintaining appropriate accommodation and ensures supervision and skill development. Serves Prince Albert, Parkland, North East, North Central and Pasquia Health Districts, as well as the Keewatin-Yathe, Mamewatan/Churchill River and Athabasca Basin Health Districts.

Paying the Bills And Taking Care of the Survivor

Paying the Bills And Taking Care of the Survivor

A brain injury may change how much the family makes and how much they must spend every month. Changes will depend on many things. Was the survivor insured? Will he be able to take care of himself? Does he require special devices to get around, to talk or to take care of himself? Is he eligible for a disability pension? Does the family need to find a new place to live? Does the survivor need help going back to school or work?

Finding out who pays for what and taking care of the survivor's money can be an extra burden for family members. Businesses and government agencies try to be friendly and open. But for someone unfamiliar with insurance and health care it can be stressful and confusing. Knowing something about your choices can make paying the bills less stressful.

In this chapter we review possible places where you can find financial assistance. We also talk about things you can do if the survivor is unable to handle their own money. Please note that this information is not meant to replace talking with lawyers, financial planners or others expert in these areas.

Help With Paying the Bills

Insurance Coverage

Many survivors will be eligible for insurance coverage. The most common types of policies are:

- ★ Saskatchewan Government Insurance - covers persons injured in or by cars, trucks and some recreational vehicles.
- ★ The Worker's Compensation Board - covers persons injured at work.
- ★ Canada Disability Pension - provides a

A brain injury may change income and expenses, knowing something about your choices can make paying the bills less stressful.

disability pension for those with a work history.
- ★ Private disability insurance from the survivor's workplace.
- ★ Private disability income plan carried by the survivor.
- ★ Home or other policy where the person was injured. (For example, school boards have insurance if the injury occurred during a school event.)

The insurance representative is the best person to tell you about the benefits of your policy. In order to receive benefits some sort of application is necessary. Often health professionals must also fill out forms on your behalf. Some benefits are very clearly spelled out in a policy, other benefits are less clear cut. More documentation will be necessary to show the need for unusual or expensive items that could possibly be covered by insurance.

Social Assistance

If the survivor or their family no longer have an income, social assistance may be able to help. Social assistance pays for food, basic phone service, clothing and a place to live. Provincial government policies say how much you get based on family size and income. People who live on a First Nations reserve must apply for social assistance with their band office. Others can find the phone number of the Social Services office nearest them in the blue pages of the phone book, under Government of Saskatchewan, Social Services, Financial Assistance. After you apply, you will be given an interview about 2 weeks later. You will need to bring letters, bills, bank statements, pay stubs etc. to show how much money you have and the cost of your housing and utilities. If your application is approved, benefits can start within days of the interview.

Persons who do not qualify for social assistance may still be able to receive extended health benefits through Social Services. Extended health benefits cover certain medical expenses for lower income families. You can phone your nearest Social Services office to see if you can get these benefits.

Asking someone else to pay for things is not easy. The following tips might help.
- ★ Learn what the insurance plan or program covers.
- ★ Ask in an assertive way for what you want. Under the stress of having to ask some people will not say what they need. They risk not getting it. Others grow angry when they are uncomfortable.

Growing angry can harm your relationship with your worker or representative.

★ Look to professionals to help you make your requests. Many times a representative cannot agree to pay for something without a letter from a professional.

What if You Aren't Satisfied

If you feel you are not getting the benefits to which you are entitled you may file an appeal. When you appeal, you may not get what you ask for, but you may help those who come after you. You also risk some hard feelings. This is something you should consider before going on.

General points on handling disagreement are discussed in the Return to School chapter. It may be helpful to think about them here. In the case of insurance plans and social assistance there are some other resources you should know about. Remember insurance companies are supposed to provide the benefits as stated in their policy. They do not have to pay for things because they will make your life easier or even because of medical necessity if they are not benefits described in the policy.

SGI has a three step appeal process.

★ Make your appeal to your personal injury representative. In this step staff members and managers from SGI look at their decision again.

★ If you are still dissatisfied a mediator can be hired from outside SGI to help resolve disagreements.

★ The final step is to take your appeal to the Court of Queen's Bench. Most people would want to consult a lawyer before proceeding to this step.

WCB has a "Worker's Advocate" who helps the survivor and the family appeal decisions. This service is free. The advocate does not have the power to reverse a decision. The Worker's Advocate number can be found in the blue pages of the telephone book, under Government of Saskatchewan, Worker's Advocates.

There is also an advocate for those on social assistance. This person helps people to make an appeal and the service is free. The

Asking someone else to pay for things is not easy.

advocate cannot reverse a decision. The phone number is available from your local social services office.

You may feel that you are not satisfied with assistance from within a plan or program. In this situation you may look to someone else to help you present your case. Two possible choices include a social worker and a lawyer. The ABI Outreach Teams have social workers who may be able to help you find an advocate. Some of the larger health districts have community social workers who may be able to help. Call your health district and ask if they have anyone who could provide guidance for you. Tips on finding a lawyer are in the "Finding Help" section of this chapter.

Helping the Survivor Handle Money

Sometimes a survivor is no longer able to make good decisions for himself. This is called incompetence. If the family believes this is the case they may decide that someone else should make choices for the survivor. There are several ways to do this.

Power of Attorney
A general Power of Attorney gives a person other than the survivor complete control over the survivor's property and finances. The survivor must have the capacity to grant this power. In legal terms, "capacity" means that the survivor is aware of what he owns, knows whom he is responsible for and can decide whom he trusts. Sometimes after a brain injury the survivor does not have the capacity to grant power of attorney. In that case trusteeship or guardianship are the only choices.

Guardianship
Under the Dependent Adult's Act one or more family members can become guardians of the survivor. A guardian can make decisions about the survivor's money and property or about how he or she lives. A Financial Guardian decides about money and property. A Personal Guardian decides how the survivor lives. You can apply to be one or both. Each type of guardian can perform a variety of duties. The guardian can carry out all of the duties or just some if the survivor can carry out some things himself.

A court decides who will be guardian and what their duties will be. If you wish to apply to be a guardian you need to follow these general steps:

- ★ Make lists of what the survivor owns, what income he has, what he owes.
- ★ Find out if the survivor has a will.
- ★ Get a copy of the application form for guardianship from a

A guardian can make decisions about the survivor's money and property or about how he lives.

lawyer or the Queen's Printer and complete it.

★ Speak to the doctor caring for the survivor and request that he write an opinion as to the survivor's competence.

★ Submit the forms and other things you have gathered to the Court of Queen's Bench.

Applying for guardianship takes time and there is lots of paperwork. It is not a difficult process, if there is no disagreement about who should be guardian within your family. The forms have been designed so that anyone can complete them, but many people prefer to work with a lawyer. There are also costs involved to file and for the court order (about $100 at the time of printing.) If you hire a lawyer you will have to pay for those services as well. You can get these fees back by charging the fees to the estate. You can also charge a certain amount per year for your duties as guardian.

The financial guardian has certain work they must do. This includes:

★ Setting up a budget,

★ Deciding whether the survivor has enough to live on,

★ Applying for services or investing money to increase income if needed,

★ Presenting records of your money handling to the courts regularly,

★ Presenting records of the survivor's assets and liabilities.

Sometimes someone outside the family will be asked to be the financial guardian. This is because of the amount of work involved. A trust company is usually chosen where there is a lot of money or property. The company will charge the survivor's estate to pay for their service. The Salvation Army can also act as a financial guardian. For a small monthly fee, designated staff in the social services area of The Salvation Army will ensure that basic finances are managed responsibly.

If you become guardian you need to think about what will happen on your death. You can specify a replacement guardian in your will. That person will need to apply to the court within six months of beginning to act

as the guardian to confirm the appointment.

If the survivor is a parent with children under 18, provisions may need to be made for the care of those children in the event of the death of the other parent. It is possible for the other parent to specify in her will a person other than the survivor to serve as guardian for children under 18. However, such a provision would be subject to legal challenge by the survivor.

Trusteeship

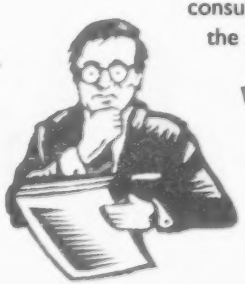
A trusteeship is a financial guardianship. The difference is that the guardian is the Public Trustee's Office. To apply for trusteeship the following steps need to be followed:

- ★ A doctor needs to sign a certificate of incompetence.
- ★ A psychiatrist has to do the same.
- ★ The chief psychiatrist for the area then issues the certificate.
- ★ An application is made to the Public Trustee's Office. The forms may be requested by calling the office. The phone number can be found in the blue pages of the phone book under Government of Saskatchewan, Justice, Public Trustee's Office. The setting up of the trusteeship usually happens in about one week.

There are costs involved in the trusteeship. All costs are taken out of the survivor's money and property. At the time of writing the costs included a $200 start up fee, 5% of the survivor's income each year, and 1% of the survivor's total assets each year.

Discretionary Trusts

Discretionary trusts may be of interest to families who want to leave money by will to a survivor who receives social assistance. Generally speaking, any additional income from the family will decrease the amount of social assistance received. Families may be able to provide a better quality of life for their family member, but find this provision of social assistance prevents them from doing so. In such a situation a discretionary trust may be set up in the wills of those who will be providing funds to the person with the brain injury. With a discretionary trust money is given to a trustee who dispenses the money to provide an improved quality of life for the survivor. A lawyer should be consulted to ensure proper drafting of the discretionary trust in the will.



Who Can Help?

There are many people who can help you and the survivor. Whom you choose depends on what you need. For many situations a good

case manager can help you. A case manager is a professional who helps people find the services they need. A case manager could find you a place to stay. He or she can help you get financial assistance. He or she can make sure you get a referral to the right health professional. A case manager can sometimes help with financial or legal matters. Unfortunately, there are not many case managers available for this sort of work. The ABI Outreach Teams provide case manager services and can help. Some of the larger health districts have community social workers or other staff who will act as case managers. However, there are situations where knowledge of the law or of finances is very important. In these cases you should think about hiring a lawyer or a financial planner.

Lawyer

A lawyer knows about laws, how courts work and how to make a legal case. They can be very helpful where you need someone to represent you or the survivor. Lawyers can be very strong advocates. A lawyer could be of help in the following situations:

★ Arranging power of attorney,
★ Seeking guardianship,
★ Writing a will,
★ Setting up a trust fund,
★ Learning about legal rights or insurance outside of the province,
★ Learning about insurance coverage and obligations,
★ Bringing suit against someone. In some cases where the brain injury has occurred through the fault of another person (particularly where adequate insurance coverage is not available), it may be necessary to consider taking legal action for compensation. A lawyer should be consulted in order to decide if it is worth your while to go to court.

Choosing a lawyer can be difficult. There are several steps you can take to feel you are getting the right one:

★ Ask friends who they deal with and whether this person does a good job.
★ Contact the Law Society (see Resources for number.) It has lists of lawyers who work in certain areas. Lawyers themselves ask to be placed on certain lists based on their particular area of practise. Names are rotated so that each

There are many people who can help, whom you choose depends on what you need.

name is given out an equal number of times. Since most lawyers have one or more areas of speciality, most are on several lists.

★ Choose a lawyer and visit them. Most lawyers will talk with you for half an hour at no charge. They will tell you how they can help. Ask about legal fees in the first phone call or meeting if it concerns you. Many legal issues are addressed on a step-by-step basis. Costs can be discussed at the beginning of each step.

Financial Planner

A financial planner helps people to decide how to manage their money. There is no legal standard as to the qualifications necessary to call yourself a financial planner. Banks, insurance companies and brokerage firms all hire people with different backgrounds to do this job. Some planners offer advice for a fee and sell products, others only sell products. Some things you can do when choosing a financial planner include:

★ Call the Canadian Association of Financial Planners. They have a list of qualified financial planners. The address is listed in the Resources at the end of this chapter if you wish to contact them.

★ Talk to a chartered accountant. He or she may be able to help or suggest someone.

★ Visit some financial planners. Ask what their qualifications are. Ask them about their experience in the area where you need help. Be clear about the kind of advice you need.

Resources

Seeking Security - Now and in the Future
Guidelines for Estate Planning and Wills for Parents of Persons with Psychiatric Disabilities
Schizophrenia Society of Saskatchewan, November, 1993

This excellent publication discusses in considerable detail topics such as social assistance, trusteeship and guardianship, wills, trusts and trustees. It is a handy resource for anyone with a family member who may need assistance because of health concerns. It is available for $6.00 plus postage and handling from the Schizophrenia Society, 438 Egbert Ave., Saskatoon, SK S7N 1X3, (306) 374-2224.

Law Society of Saskatchewan
1100 - 2500 Victoria Ave., Regina, SK S4P 3X2
Tel: (306) 569-8242

Lawyer Referral Service
1-800-667-9886

The Canadian Association of Financial Planners
1710-439 University Ave., Toronto, Ontario M5G 1Y8
Tel: 1-800-346-2237 Fax: (416) 593-8459
email: planners@cafp.org website: http://www.cafp.org

Public Legal Education Assoc.
115-701 Cynthia St., Saskatoon, SK S7L 6B7
Tel: (306) 653-1868 Fax: (306) 653-1869

Notes

Sexuality

Sexuality

Sexuality involves everything about ourselves, and is expressed by our social interactions and the roles we fulfill. Brain injury may alter a survivor's expression of sexuality. Mother, father, child, lover, friend, employee - all are roles that may be affected by an altered expression of sexuality resulting from a brain injury.

Since many people regard sexuality as a private matter, they are hesitant to bring the topic up. The purpose of this chapter is to let you know that sexuality is an important issue and you can feel free to ask questions.

Concern about the survivor's expression of sexuality will vary depending on his age and role at the time of brain injury. If the survivor is a young child, you may not be concerned with the issue. If the survivor is an adolescent or young adult hoping for a romantic relationship, or your spouse, you may be very interested in the topic.

Several possible changes and concerns are discussed here, but if you have questions about topics not covered, do not hesitate to ask the health professionals working with you and the survivor.

Common Changes

The most common changes for a survivor are either a decrease in interest in sexual relationships or uninhibited behaviour in inappropriate situations. In both cases, it is important to remember that this behaviour is the result of the brain injury.

- Cognitive difficulties, such as uninhibited speech or behaviour, poor social judgment and misunderstanding social cues, are often the source of inappropriate behaviour. The survivor may say things out loud that others think but do not say. For example, you may think someone attractive; the survivor may bluntly tell a stranger they find them attractive.
  A survivor may interpret friendliness as a sexual approach, and may be surprised by

Sexuality is an important issue and you can feel free to ask questions.

the rejection they experience when they respond sexually.

Some changes may leave a survivor vulnerable to exploitation. For example, impaired judgment may prevent them from recognizing a potentially dangerous situation, or they may lack the sixth sense that tells them someone who seems friendly is really seeking to take advantage.

- Social skills are an important part of sexuality, and difficulty with them will affect a survivor's relationships with others. If he has memory impairment, shows little change in facial expression, or takes longer to put thoughts into words, he may find it difficult to form friendships. Limited social relationships will reduce the possibility for a romantic relationship. This is a cause of much anxiety for adolescents and young adults.
- Depression is a common occurrence for both survivors and their families. Being depressed or feeling down can influence one's sexual desire. In this case, it is more important to treat the depression itself than the symptom.
- Parents of a child with a brain injury may find their sexual relationship changes. Stress, fatigue and emotions such as anger, guilt and depression can affect sexual interest.
- A spouse who becomes the caregiver may find it difficult to maintain a sexual relationship, because the roles of caregiver and lover do not mix easily. Many caregiving spouses report a variety of reasons for their declining interest in sex. They may not have a lot of energy. The survivor's appearance, behaviour and intellectual abilities may change, and he may no longer be the kind of person the spouse would have chosen as a sexual partner. Survivors may appear to have an increased interest in sex, because they cannot remember when they last had intercourse with their partner. Keeping a written log may help such a situation.

Coping with Changes

When the survivor behaves in a sexually inappropriate manner, deal with the situation in the same manner as any other inappropriate behaviour. Describe the behaviour to him, explain why it is inappropriate, and provide an appropriate alternative action.

To prevent inappropriate behaviours or improve learning of appropriate ones, discuss and practice appropriate behaviour for particular situations. Memory difficulties may make it necessary for you to frequently review and practice

these lessons. If inappropriate behaviour persists, use a time out. Tell the survivor his behaviour is inappropriate and that you are going to another part of the house and will not interact with him until the behaviour stops.

Talking about Sexuality

Even though you may not feel comfortable discussing issues of sexuality with others, it is important for you to talk about what is happening and how you are feeling. Speak to a health professional who is familiar with brain injury and its effects, or talk to the parents or spouse of another survivor.

As a spouse, you may have feelings of guilt and anger about your changed relationship - these feelings are normal. Talking about them to a knowledgeable person can help prevent further stress and depression.

Resources

Head Injury Rehabilitation: Sexuality After TBI
W. F. Blackerby, HDI Professional Series on Traumatic Brain Injury, No. 10

This booklet is written for health professionals, so family members may find the technical language difficult. It is, however, one of the few concise references that is easily available. It can be borrowed from members of the ABI Outreach Teams and through interlibrary loans from your local library.

Sexuality and the Person with Traumatic Brain Injury: A Guide for Families
by Ernest R. Griffith and Sally Lemberg.
F.A. Davis Company, 1993

Notes

General Health

General Health

Nutrition

Brain injury may change a survivor's nutritional status. For some, damage to the brain causes an inability to feel full or feel hungry, causing them to eat too much or too little without realizing it. Memory problems may also affect food intake. Others may have an altered or absent sense of taste or smell.

* The simplest way to manage many nutritional concerns is to create a meal plan and record what the survivor is eating. In this way, if he has problems remembering when he last ate, or has no feeling of fullness, he can look in the record and see.

Canada's Food Guide

The following points from Canada's Food Guide to Healthy Eating provide basic information on good nutrition.

* Enjoy a variety of foods. Emphasize cereals, breads, other grain products, vegetables and fruit. Ensure that individual needs for energy, protein and other nutrients are met. Nutritional assessment and follow-up by a dietitian may be required. Most health districts employ dietitians whom you can contact directly.

When choosing foods, take into account any problems the survivor has with swallowing or food allergies. A speech-language pathologist can assess and treat swallowing problems; a dietitian can help with food allergies. Speech-language pathologists may be accessed through your local health district or the ABI Outreach team.

* Choose lower fat dairy products, leaner meats and food prepared with little or no fat.

If the survivor is overweight, you may need to control portion sizes as well as fat content. If the survivor is underweight or has increased energy requirements,

Eating well is an important part of recovering from illness and maintaining good health.

CANADA'S

Food Guide

TO HEALTHY EATING

Enjoy a variety of foods from each group every day.

Choose lower-fat foods more often.

Grain Products
Choose whole grain and enriched products more often.

Vegetables & Fruit
Choose dark green and orange vegetables and orange fruit more often.

Milk Products
Choose lower-fat milk products more often.

Meat & Alternatives
Choose leaner meats, poultry and fish, as well as dried peas, beans and lentils more often.

however, you may need to provide higher fat foods to achieve and maintain a good weight.

* Achieve and maintain a healthy body weight by enjoying regular physical activity.

  In addition to healthy eating, physical and/or recreational activities or therapy exercises suited to the survivor's abilities and lifestyle are recommended. Physical, recreational or occupational therapists may provide advice on the kind of activities most suitable for the survivor.

* Limit salt and caffeine.

  Limiting salt may help control high blood pressure and fluid retention if the survivor has these concerns. The caffeine found in coffee, tea, some colas, and chocolate is a stimulant. The survivor's ability to tolerate caffeine may be very limited and it may be best to avoid all caffeine.

  Even if the stimulating effect of caffeine is not a problem, Health Canada suggests consumption of no more than four cups of brewed coffee (or the caffeine equivalent in other foods and beverages) per day.

* Choose foods from the four food groups.

  Canada's Food Guide to Healthy Eating identifies the four food groups and recommends the number of servings per day required by healthy Canadians. You can obtain a copy of Canada's Food Guide by calling a dietitian in your health region. Factors such as age, weight, sex, activity and medical concerns will influence how many servings are required from each of the four groups. Serving sizes can be adjusted to meet individual needs. Other foods such as butter, salad dressing, jam, candy, pop, chips, herbs and spices are not part of the four food groups, but add taste and enjoyment when eaten in moderation and as tolerated.

Eating well is an important part of recovering from illness and maintaining good health. Follow Canada's Food Guide. If you are concerned about the survivor's nutritional needs, ask his health care team for a referral to an outpatient dietitian.

Medications

Since taking more than one medication at a time can lead to drug interactions, it is important for both the doctor writing the prescription and the pharmacist to know

which drugs are being taken. If the survivor has problems with memory, he can carry a list of his medications to show the doctor and the pharmacist, or you can accompany him and take the list. Go to the same pharmacy for all your prescriptions, and share the list with the pharmacist even when buying non-prescription or over-the-counter drugs, since interactions can occur with these as well.

Follow Instructions

It is essential to follow instructions when taking medication. Drugs are most beneficial when taken in the right dose, at the right time, in the right way. Not following instructions may prevent the drug from doing its job.

Pharmacists will usually give you an instruction sheet each time you fill a prescription. If they do not automatically give you one, ask for it. It will provide important information, such as common side effects and what you can do about them, drugs that should not be taken at the same time, and special instructions to ensure the drug is most effective, such as taking between meals or with food. Take the time to discuss any questions with your pharmacist.

Memory Aids

If the survivor has problems with his memory, there are several aids available that can help him take medications correctly. Purchase a dosette, a plastic container with separate pill compartments for different times of the day and different days of the week. Ask your pharmacy if they can put medications in individual bubble packages with labels showing the time and day pills in each package should be taken. ABI Outreach Teams may provide other helpful suggestions.

Commonly Used Medications

- Anti-convulsants: if the survivor has had seizures (convulsions) following the injury, he will probably be given a prescription for an anti-convulsant. The purpose of these drugs is to prevent seizures.

  The need for anti-convulsants will be re-evaluated by the survivor's physician on an ongoing basis. The drug may only be needed for a few months, but you should discuss the expected duration with the

Medication is most beneficial when taken in the right dose, at the right time, in the right way.

physician. Do not increase or decrease the dose without first consulting the physician.

- ★ Anti-depressants: originally used to treat depression, this class of drugs is now proving useful in other situations as well. The survivor may be given anti-depressants to help him have "restorative" sleep - the kind of sleep that makes you feel well-rested. They may be prescribed to help deal with certain types of pain, or they may be given to help decrease impulsiveness and emotionality, without causing the same side effects as other drugs. And of course, they are used to treat depression.

Some survivors, and their caregivers, experience depression. Depending on the level of depression, the physician may prescribe anti-depressants to help relieve feelings of sadness and hopelessness.

- ★ Anti-spasmodics: following brain injury, muscles in certain parts of the body may be tighter than usual. This may cause pain and altered use of the affected joints. Anti-spasmodic drugs help loosen muscles, which reduces pain and makes it easier to move joints properly.

- ★ Analgesics (painkillers): survivors may experience some level of pain following a brain injury. Headaches and pain from tight muscles are two of the more common reasons for taking analgesics. Non-prescription pain-killers, such as acetaminophen, are often useful for occasional pain relief. In more severe or chronic cases, a prescription medication may be required.

- ★ Psychotropics: if the survivor has problems with impulse control, meaning he does things without thinking about the consequences of his actions, he may be given psychotropic drugs. Acting without care for consequences can lead to embarrassing and even dangerous situations, and psychotropics may be helpful in controlling some behaviours.

Alcohol

Survivors of brain injury should abstain from alcohol consumption. Alcohol affects the brain's ability to function. When the brain is already damaged, the effects of alcohol are more pronounced. Alcohol affects the brain in the following ways:

- ★ Limits recovery,
- ★ Increases problems with balance, walking and talking,

- ★ Increases the likelihood of saying or doing things without thinking,
- ★ Interferes with the ability to think and learn new things,
- ★ Increases the chance of becoming depressed,
- ★ Increases the chance of having a seizure,
- ★ Increases the chance of having another brain injury.

As this list demonstrates, using alcohol after a brain injury increases problems. Your family may choose to assist the survivor by not drinking yourselves.

Some survivors may have been using alcohol to excess before the injury. If this is the case, additional help may be needed to change this destructive pattern. Find a health professional familiar with both alcohol abuse and brain injury to help you.

Illegal Drugs

Most street drugs, such as marijuana and cocaine, hold the same dangers for survivors as alcohol. If the survivor did not use drugs before his injury, he needs to know it is important to continue to abstain from use.

If he did use drugs before the injury, he may need the assistance of experienced drug counselors to stop. Continued drug use will put the survivor at an extremely high risk of further brain injury.

Ongoing Physical Problems

Ongoing Physical Problems

Fatigue

The material in this section is condensed and adapted from Managing Fatigue: a Six Week Course for Energy Conservation.

Fatigue is a common problem among survivors of brain injury. The survivor may not have the energy to do the things he used to do. This energy shortage or fatigue may be a temporary situation or a life-long problem. This section discusses basic concepts to help the survivor make the most of his energy.

What to Expect

It is likely, especially soon after discharge from hospital, that the survivor will not be able to do all the things he did before the brain injury. He may experience fatigue in physical or mental ways. For example, he may:

- ★ Feel as if his whole body is worn out, or just certain parts are tired,
- ★ Find it difficult to concentrate or do other, activities that involve thinking, focusing or remembering (tiring activities for survivors of brain injury,)
- ★ Become "grumpy" or "short" with others,
- ★ Say he is tired, lack energy, or lack the desire to do anything,
- ★ Become frustrated and feel "down" because his overall activity level is reduced,
- ★ become distressed that he can not do the things he used to do.

Stress from feeling frustrated or down also can increase fatigue. This creates a cycle of fatigue causing stress, which then increases fatigue.

- ★ Understanding that the survivor is operating at a different speed will help everyone - survivor, family members and friends - adjust their expectations accordingly.

Managing Energy

To stop this cycle of fatigue or prevent it happening, the survivor needs to manage his energy. This involves developing an energy

A daily schedule can be a big help in budgeting, saving and spending energy.

"budget," saving as much energy as possible, and spending energy on meaningful things.

To budget energy, the survivor may need help with setting priorities, evaluating standards, and playing an active role in decisions.

- ★ Setting priorities means deciding what activities are most important, and organizing the daily routine to accomplish these activities.
- ★ Standards are expectations for the performance of an activity, such as how often something is done or how well it is done. Changing standards can free up energy and allow the survivor to do things he really wants to do. As part of the re-evaluation, he may gradually stop doing certain things.
- ★ Playing an active role in decisions about how he will spend his energy will give the survivor a sense of control over his life. It might be helpful to make a list of activities and have the survivor decide what he will do, what he won't do, and what he would like to do.

Learning to Rest

Resting is one of the best ways to save energy. Since it is important to rest before becoming fatigued, alternate rest and activity periods. This is called pacing. By alternating a tiring activity with a rest period, the survivor will accomplish more.

There are many ways to rest: sitting, lying down, spending time in a quiet environment without distractions, sleeping, or engaging in a quiet hobby. You and the survivor will need to experiment with what type of rest works best, and when, how long and how often he needs to rest.

Using a Daily Schedule

A daily schedule can be a big help in budgeting, saving and spending energy. To create a daily schedule, start by inserting rest times through the day, then schedule activities around the rest times. Schedule the more difficult activities for times the survivor is likely to have more energy, such as after a rest. The survivor will spend less energy if his day is planned so that tasks requiring mental activity (concentration, thinking, problem-solving) are broken into shorter periods of time.

- ★ A daily schedule not only provides a routine for the day, it functions as a memory aid and gives the survivor a sense of control and accomplishment.

Headaches

Headaches are quite prevalent after a brain injury. Their severity usually decreases over time, although some survivors are bothered by headaches for years. For severe headaches, it may be important to see a neurologist.

There are different types of headaches.

★ Muscle tension headaches tend to start from the back of the head and move around the side or over the top to the forehead. They are often the result of stretched head and neck muscles, caused by the force of the head jerking rapidly forward and backward at the time of injury.

★ Migraine headaches tend to occur in the front of the head. The survivor may complain that his forehead or temples throb, he may be sensitive to light, feel nauseated or actually vomit. Migraines may be caused by damage done to small blood vessels in the brain at the time of injury.

★ Some survivors report a very sharp, sudden pain in the head, but because the pain usually only lasts a short time, doctors may not treat this type of headache.

★ Analgesic rebound headaches are actually caused by the use (usually overuse) of analgesics (painkillers) for headaches.

Treatment Tips

Treatment for headaches varies. The first step is for the survivor - or you, if he has trouble with his memory - to give the doctor a good description of the headache. This will help the doctor determine the best way to treat it. In difficult cases, it may be necessary to see a neurologist for help in controlling the headaches.

For muscle tension headaches, the following may prove helpful:

★ Physiotherapy treatment, including exercises as instructed by the therapist.

★ Experiment with different pillows, including using a small, rolled towel under the neck. Poor neck position while sleeping can increase headaches.

★ Ensure the prescription for glasses is

Although headaches can be difficult to cope with, they are seldom a sign that something else has happened or that the situation is getting worse. They will usually get better over time.

correct. Straining while reading or watching television can increase muscle tension.

- ★ Read or watch television for short periods of time only, since the effort of concentrating may increase tension.
- ★ Massage uncomfortable muscles.
- ★ Exercise neck and shoulders frequently by rolling the head in a 360 degree circle and rolling the shoulders forward and backward.

Migraine headaches can be very difficult to treat. Medications are frequently used, but it can take time to find the right medication. It is very important to take medications exactly as prescribed. If the survivor has trouble with his memory, you may need to remember for him. You can also provide an aid, such as a watch set to alarm at medication time.

The following suggestions may help for migraine-type headaches:

- ★ Lie down in a dark, quiet room as soon as a headache starts. Bright lights and noise can make migraines worse.
- ★ Wear dark sunglasses (very dark ones are best.)
- ★ Keep track of what is eaten prior to a headache, as some foods can trigger a migraine.

Several general tips can help ease muscle tension and migraine headaches:

- ★ Get adequate rest. Fatigue can often cause headaches.
- ★ Practice deep breathing and relaxation exercises for 20-30 minutes per day. Many headaches are associated with stress, and these exercises are excellent for relieving stress. (Ask a psychologist, nurse, physiotherapist or occupational therapist to teach you.)
- ★ Avoid noisy environments and too much stimulation.
- ★ Do not concentrate too long on one thing.
- ★ Stop smoking.
- ★ Stop using caffeine beverages or limit to 3-4 cups per day.

If headaches are severe and difficult to treat, you and/or the survivor can keep a headache journal. In the journal, rate the severity of headaches on a scale discussed with the doctor, such as 1 to 10, with "1" being no headache and "10" being the worst. Also write in the journal what events happened before the headaches. If a pattern can be seen, steps can be taken to prevent headaches.

- ★ Some over-the-counter medication can have serious side effects, such as liver damage, so be sure

the survivor does not take more than the recommended daily dose. If he is exceeding the daily dose or feels the daily dose is inadequate, talk to the doctor about other solutions. This assumes the survivor is not exceeding the daily dose due to memory difficulties.

Dizziness

Dizziness is another common symptom that tends to get better with time. It can be described as a feeling of imbalance, lightheadedness, drunkenness, blurriness or a turning sensation. It can last for seconds or hours, and may be severe enough to make it difficult to climb, bend, or move around. Dizziness may result from injury to the inner ear, eyes, or neck, or it may be due to emotional distress caused by the injury.

- ★ Moving quickly can make dizziness worse. Survivors can adapt by moving slowly, especially when changing from a lying to a standing position.
- ★ If necessary, see an eye specialist, ear, nose & throat specialist, or physiotherapist for treatment. The specialist can help determine the exact cause of dizziness; the physiotherapist can provide exercises to help cope with dizziness.

Resources

Fatigue

Managing Fatigue: a Six Week Course for Energy Conservation
Tanya Packer, Nicky Brink, Adele Sauriol
Tucson, Arizona, Therapy Skill Builders, 1995

Headaches

If you have access to the Internet, the following site is a book for family and survivors of brain injury. It has a helpful chapter on headaches.

http://www.tbiguide.com

Notes

Resources

Resources

Acquired Brain Injury Partnership Project Resources

Provincial Offices

Provincial ABI Coordinator
Saskatchewan Health Community Care Branch
T.C. Douglas Building
3475 Albert St., Regina, SK S4S 6X6
Tel: (306) 787-6949 Fax: (306) 787-7095

Provincial ABI Prevention & Education Coordinator
Saskatchewan Health Community Care Branch
T.C. Douglas Building
3475 Albert St., Regina, SK S4S 6X6
Tel: (306) 787-0802 Fax: (306) 787-7095

ABI Outreach Teams

SK Central ABI Outreach Team
Saskatoon City Hospital
710 Queen St., Saskatoon, SK S7K 0M7
Tel: (306) 655-8448 Fax: (306) 655-8269
Toll Free 1-888-668-8717

SK North ABI Outreach Team
1521-6th Ave. West,
Prince Albert, SK S6V 5K1
Tel: (306) 765-6631 Fax: (306) 765-6617
Toll Free 1-866-899-9951

SK South ABI Outreach Team
Wascana Rehabilitation Centre
2180-23rd Ave., Regina, SK S4S 0A5
Tel: (306) 766-5580 Fax: (306) 766-5144
Toll Free 1-866-766-5617

Everyone in Saskatchewan has access to consultation with the ABI Outreach Teams. Call the Team in your area; they can direct you to the services closest to you that fit your needs.

Self Help Groups

Saskatchewan Brain Injury Association
1702 - 20th St. West, Saskatoon, SK S7M 0Z9
Toll Free: 1-888-373-1555 Tel: (306) 373-1555 Fax: (306) 373-5655

Written Resources

There are huge numbers of books, pamphlets, one-page handouts and magazine articles on brain injury. Contact the SK Brain Injury Association or one of the ABI Outreach Teams and tell them what kind of information you are looking for. They all have libraries of written information specifically on brain injury, and many of these resources are written for persons with brain injury and their families, rather than medical people.

These agencies also have audio-visual material, such as videos, which may be easier for some people than written material. They have resources that deal with specific changes, such as memory, planning, and inappropriate behaviour, as well as personal stories from people who have survived brain injury.

Personal stories are not only inspiring, they can be reassuring, in that they can help you see you are not alone.
In addition to the books mentioned in individual sections, the following resources are excellent.

Brain Injury
Coping with the Results of Brain Injury
Glenrose Rehabilitation Hospital, 1993

The Survivors
Glenrose Rehabilitation Hospital, 1995

These are available from all ABI Outreach Teams in Saskatchewan or can be ordered from:
Glenrose Rehabilitation Hospital
10230-111 Avenue, Edmonton, AB T5G 0B7
Tel: (403) 471-2262

Children's Health Resources

While they do not specialize in brain injury information, the following resource centres do provide information specific to children's health care issues, including brain injury.

Family Resource Room
Kinsmen Children's Centre
1319 Colony St., Saskatoon, SK S7N 2Z1
Tel: (306) 655-6871 Fax: (306) 655-1449

The Centre has part-time hours, so phone ahead. The coordinator is very willing to help you find information.

Children's Resource Centre Dept. of Pediatrics, Royal University Hospital
103 Hospital Dr., Saskatoon, SK S7N 0W8
Toll free 1-888-990-5437 Tel: (306) 966-8639
Fax: (306) 966-8110
e-mail: childrens.health@sdh.sk.ca

The Centre is open Monday to Friday from 9:00 a.m. to 4:00 p.m. To ensure the coordinator is there, phone ahead. The coordinator is available to help you use the Internet to search for material and may be able to get the information you want through the Health Science Library at the University of Saskatchewan.

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Phone Numbers

Project Supported By:

SGI

Saskatchewan Health

Saskatoon Health Region